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ABSTRACT

The manual is designed to provide basic information on disabilities to future respite providers. The first chapter examines the nature and characteristics of handicaps in general as well as specific types, such as cerebral palsy, deafness, mental retardation, and behavioral disabilities. The chapter also introduces changing social notions regarding the handicapped. The next nine chapters address the following topics (sample subtopics in parentheses): family feelings and needs of the handicapped (parental reactions and adjustments); home and safety guidelines (inside, outside, accident prevention); health management (medication, specific problems such as seizures and choking); behavior management (increasing and decreasing target behavior); feeding and nutrition (basic meal planning, eating skills, body positioning); communication (alternative communication methods, care of hearing aids, play); physical management and adaptive equipment (wheelchair and stroller considerations, transferring, braces and splints); dressing, grooming, toileting and homemaking; and leisure time activities (activities and community resources). (CL)

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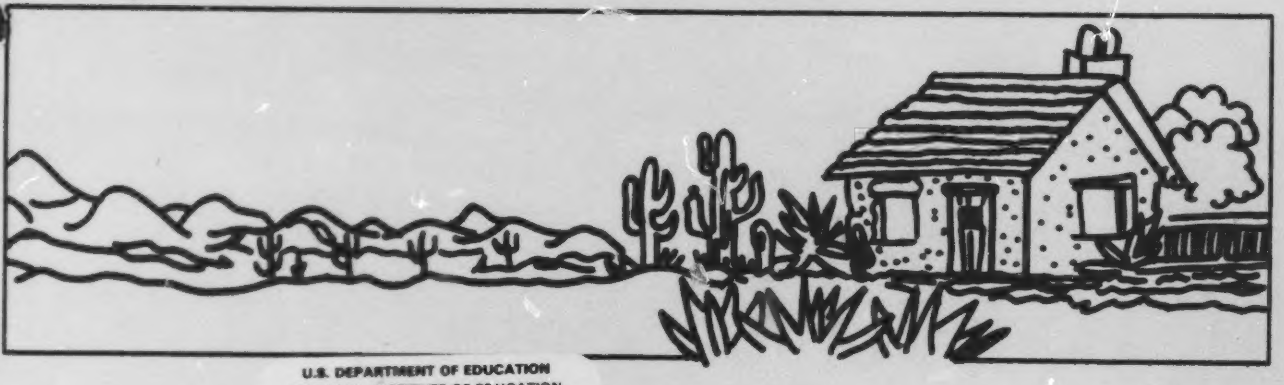

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FAMILY SUPPORT SERVICES

RESPITE • SITTER • IN-HOME PROGRAM TRAINING MANUAL

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CHAPTER I: WHO ARE THE HANDICAPPED

A. Introduction

1. It is no accident that this book begins with a question. There's a good chance that ever since you were first interested in becoming a respite provider, you have had a lot of questions about what the work would be like. Maybe one of the first questions you asked yourself was "With whom will I be working?" The second question was probably something like "Can I handle it?"

2. You should be able to find some answers to these very natural questions in this course. Later in the book, you will find examples and exercises of what you actually will be doing when you are a respite care provider. In this chapter, you will be introduced to some of the kinds of children and adults with whom you will be working, and to their families. You will also find a list of textbooks and references at the end of this chapter, but these do not always "translate" into pratical information to use in real life--and of course that is where you will be working. So concentrate on functional information; that is, information about what happens to children as a result of their handicaps, the kinds of problems they have, and how all of that will affect your work with them. For instance, while it may be interesting to know why Johnny happens to have a hearing loss, you'll probably find it more useful to know how Johnny's hearing loss affects his ability to talk to you.

3. You should also be aware of some changing attitudes towards handicapped people, and some social trends that affect the way that they live in our society. Before going into these questions and the specific details about different kinds of handicaps, there are some general comments about handicapped children that need to be made.

B. Handicapped Individuals Are Different--But Not Different

1. The old cliche that tells us "No two people are alike" is certainly true of handicapped persons. It is sometimes all too easy to slip into thinking that people with a certain kind of handicap are exactly the same--and that because they have a particular handicap they have the same problems or personalities. But that is almost as unreasonable as saying that all people with red hair are alike. So it is important to remember that no two handicapped individuals are alike. Most important, there are differences in the way handicapped people adapt to or cope with their handicaps.

2. We must also recognize that there are some important similarities -- similarities among handicapped individuals and between them and their normal peers. We mean, of course, that we all share certain human needs, and the handicapped are no exception. We all need to have attention, love, warmth, care, affection, discipline, companionship. The list of needs could go on for pages because it is a list of human social needs, and these are many and varied. These needs are almost as urgent as our basic needs for food and shelter. In fact, studies have shown that people who are deprived of social contacts can suffer emotional starvation that even affects them physically--it can retard their growth the same way that physical starvation from lack of food can retard their growth. Yet here

again, it is too easy to make some wrong assumptions about handicapped people: to assume, for instance, that because Susie has difficulty speaking she does not want to communicate; or that because Bill is withdrawn he does not need other children or want to play with them; or that because Mary has cerebral palsy she cannot take part in games and other play. So, the main message is this: handicapped people are unique individuals; yet, just like everyone else, they have basic human and social needs that must be met.

C. Families Have Needs, Too

1. Another general statement about handicapped children that will be important in your job is this: raising a handicapped child is difficult work, and it can cause great stress in the lives of the child's family. When parents and families find out that their child is handicapped, they begin to look within themselves for all the experience and knowledge they might have to help them cope with the many new situations they have to face. Often, they feel alone and isolated and cannot think of any reference point for help — a handicapped person they might have known, or families in similar circumstances who can offer advice.

2. Several years ago, the National Association for Retarded Citizens called its annual conference "Educating the 24-Hour Child." Perhaps that is the crux of the issue for handicapped children's families: they are on call all the time, with precious little relief from the special responsibilities and challenges of caring for their children. In addition to feeling alone and isolated, they do not have the mobility of other families. It is not always easy to take handicapped children out or to find sitters for them. If the child's handicap causes him or her to look or act "different," the family is always "on view" and can rarely find the privacy that other people enjoy. If you have ever had anything so minor as a cut on your face requiring a bandaid, you know how difficult it is for you not to feel conspicuous, and for other people not to stare at you or wonder what happened.

3. You can imagine, then, what constant anxiety and concern are felt by families who must live with and try to explain "differences" all the time, while at the same time trying to create a family life that is as normal as possible.

4. Families of handicapped children develop incredible strengths and skills as they learn to cope with these unusual stresses. But it is important to remember, always, that these strengths do not come easily, and that they may have been developed at terrific physical, economic, and emotional cost to the family. Whatever contributions you can make to reducing these stresses and costs will be appreciated. This is the most important task of a respite provider!

D. There Are Many Varieties of Handicap--and Many Handicapped People

1. One of the problems in identifying handicapped people is knowing where to start or stop. According to some ways of looking at this, anyone is handicapped who deviates from "normal" at all. Of course, by that reckoning, anyone who had less then 20/20 vision would be on the list, and

that would probably mean that more people are handicapped than not--so that is too broad a view. Another way tends to be too narrow: for instance, saying that only people who reach a certain level of impairment, with only certain kinds of problems, are "really" handicapped, whatever that means. Such a view leaves out a lot of people who are in need of some help.

2. Some people talk about the difference between being handicapped and having a handicap. They mean that a person may have a handicap but has overcome it or learned to accommodate to it so well that he or she does not have impaired functioning. For instance, there could be a hard of hearing person who has a hearing aid, knows how to use sign language and lip read, and can function completely independently. And yet, that person's need for assistance--for the hearing aid, the sign language, and so on--continues for as long as he is hearing impaired. So in one sense, he never stops having the handicap. We see, then, that trying to define and categorize handicaps is complicated; and that any system of identification or definition, including our own, is going to be arbitrary.

3. Handicaps can arise from a very wide variety of causes--"accidents" or "errors" or injuries that occur before or during birth; during infancy; or at any time during a person's life. The causes can be found in the environment, or in various diseases, or in a person's genes and cells. One can be as handicapped by an automobile accident or lead poisoning as by a birth defect. Sometimes there are handicapping events that happen very early, but the conditions they cause remain "silent," and are not "heard from" until much later--maybe as late as when a person is a teenager or even middle aged. Often, the symptoms of a handicapping condition are evident at birth. In other cases, the handicap is not noticeable until a child begins to miss certain milestones--is very delayed in walking, or talking, or learning how to take care of himself, like dressing or feeding. Sometimes a handicap occurs as a single problem, such as a hearing loss. Other times they occur as multiple problems, like a hearing and vision loss together. Still other handicaps occur as syndromes, or clusters of problems that develop together.

4. Some handicapping conditions are more noticeable than others. Some handicapped people are immediately identifiable because their features, or posture, or gait, or behavior are markedly different from most people's, as a result of their impairment. Other handicaps, like mental retardation or hearing loss, are usually more hidden, but not less disabling because of that. The way that handicapped people adapt to their handicaps also varies, as we noted earlier. One cannot help but think of remarkable people like Helen Keller and Franklin D. Roosevelt, who lived such vigorous lives despite devastating handicaps. That kind of courage and motivation is often found in handicapped people. It is important to note that the way other people react to the handicapped, and the expectations they have for that person may have a great deal of impact on how he or she adapts and grows.

5. An example of such adaptability involves two girls who were classmates through junior and senior high school and who often walked to and from school together. Margery was an honor student and served on many committees and in several clubs. She was kind, considerate, and always pleasant. The two girls walking to school together appears very natural

and unremarkable until one realizes that the reason for this companionship, when it began, was that Margery's mother wanted her to have someone to walk with because she has epilepsy. But it was so easy to forget that fact because of Margery's ability to lead a very natural, relatively unimpaired life. Everyone knew that she had a problem, even a medical problem and had helped to take care of her during her seizures. But they always thought of her first as a person, and only then as a person with a problem. Margery's naturalness made it easy for other people to feel comfortable and at ease with her. But it is also true that their friendliness and naturalness with her helped her to lead a close to normal life. We can all think of handicapped people we have known whom we think of as persons first, and only then as persons who have problems.

6. It should be obvious from this discussion that there are a lot of handicapped people in our society. To give just a few figures: some estimates show that one out of every ten people has some hearing loss. One child out of every 650 will be born with Down's syndrome, a cluster of problems that includes mental retardation. One in every 650 persons has cerebral palsy. One out of every 14 persons is born with a defect that will interfere with that person's ability to function.

7. Perhaps you are still wondering whether you will be able to handle your work with handicapped children. Part of that concern is really a fear of the unknown--what you think is your lack of familiarity with handicapped people. But if you stop to consider the figures just discussed, you'll realize that you probably have known many more handicapped people than you thought you did. After all, there are so many of them. And so many more handicapped people are now participating more fully in our communities. Many who used to live in institutions are now living in their home communities; some who have always lived there but never went outside their homes are now much more visible--in schools, on buses, in playgrounds. So you have no doubt interacted with many handicapped people, and you may not even have realized they were handicapped if their handicaps are of the more "hidden" variety.

8. Reflect seriously on your question, "Can I handle it?" For most of you, the answer is: of course you can. You've probably already done it. But if you have any doubts, and it is expected that many people will, keep them in mind during the course. This training program is designed to help people decide if they really want to be respite providers or not, before they are actually in that situation. This program will help you to acquire some skills that will make your work easier, and more enjoyable.

9. Having made these general comments, we can now turn to more specific answers to the original question: Who are the handicapped?

E. Some Handicapping Conditions

The children with whom you will be working have some areas of limitation in their lives due to varying causes. They may have disabilities in one body function or two, or more. They might not stand or walk, hear or speak, see or learn as you and I. Some of the medical problems and disabilities which children receiving your services might have are briefly described here. You should, of course, consult other references to learn as much as you can about the specific handicapping conditions of the person with whom you will be working.

F. Paralysis

Among the many causes of paralysis, multiple sclerosis, brain tumors, spinal cord injury from accidents, muscular dystrophy, and spina bifida are the most common in children. A child may have one or more of his limbs partially or totally paralyzed. In some cases, there is hope that the degree of paralysis can be improved through therapy while in other cases, the paralysis almost always becomes more severe despite our best efforts. Today, there are many technically advanced aids to help paralyzed persons achieve maximum mobility.

G. Cerebral Palsy

1. There is a considerable range of severity in the nature of symptoms of cerebral palsy. Some who have cerebral palsy walk with scissoring, floundering movements, awkward armflinging, and head tossing. Some speak with difficult gutteral sounds. Some not at all. Some people show one or a combination of symptoms such as involuntary jerking movements of different muscle groups, a slow, writhing type of constant movement, mainly in the fingers, poor sense of balance, tremors, and spastic muscles. Occasionally there is mild to severe impairment of intelligence; sometimes normal intellect may be hidden behind difficulties of communication.

2. Children who have cerebral palsy often have great difficulty dressing and feeding themselves. You may be required to assist them by following specific steps and methods which may seem strange to you, yet are necessary for them to become self-sufficient.

H. Blindness and Vision Impairment

1. Vision impairments do not in themselves cause a severe disability to living a full life. Those children you will serve who have a visual problem will likely have another problem as their primary disability. Some will wear glasses or contact lenses; few will wear both. Some will wear neither.

2. Children born with or acquiring blindness in infancy may have various mannerisms, or repetitive motions, called blindisms. They usually can be eliminated by following the advice of the doctor or occupational therapist guiding the child's progress.

3. Infants and toddlers need encouragement to touch things, to learn to use their fingers for gathering of information. They often need special help to learn how to crawl and then walk since limited vision reduces the motivation to move toward objects and people. Often, because a youngster feels insecure, you will find those of toddler ages crawling, gaining the security he needs while he explores his surroundings. Older children with little usable vision might read braille and may use a cane to walk about, or they may use a guide dog. There are some easy instructions which you can get from counselors of people with blindness which can assist you in traveling about with a child with blindness.

4. One type of blindness which isn't widely understood is narrow angle or

tunnel vision. It is just as the name implies: like looking into a long tunnel with a light at the end, one can see in a small circle straight ahead but not to the sides. Many of the people who have this type of blindness can read regular print but cannot walk about unaided.

I. Deafness and Hearing Impairment

1. There are many kinds of hearing loss, ranging from mild, missing some soft sounds, to profound, missing most sounds even when wearing an aid. Those with mild to moderate hearing losses have a "hearing impairment." Those with severe to profound losses have "deafness." Some can be assisted with amplification (a hearing aid), others not.

2. Those children who have a hearing impairment or deafness receiving your services will likely have another disability. The combination of the two greatly interfere with the child's ability to develop without considerable special assistance. A child with a hearing loss, which is adequately assisted by a hearing aid, will need you to speak clearly, but you needn't speak abnormally slowly or loudly. You may need to be more attentive to his speech as it might not be easily understood.

3. The child with a severe to profound loss (deafness) might also wear an aid, but will seldom use speech as his main mode of communication. Most likely he will use Total Communication or some part of it: speech, sign language, finger spelling, speech (lip) reading, reading, and writing print. There are several "dialects" in sign language, including manual English, signing exact English, and American sign language. You will want to know which the child is using and do some studying.

4. Though there are very few children with hearing and vision losses you may have occasion to serve one. Often these children, whose disability is generally referred to as "deaf-blindness," communicate most often by touch. Some learn speech by a method called Tadoma. They will place their fingers on the side of your face and throat to feel the vibrations of your voice and the motions of your mouth and jaw. Also, they may need to hold their hands on your hands while you sign or finger spell.

J. Seizure Disorders (Epilepsy)

1. Epilepsy is the general name given to the symptoms of a number of disorders of the nervous system. Since epilepsy appears in different ways, two children with epilepsy may show very different symptoms. During a seizure, a child often loses consciousness and control of his muscles for a short time. He is affected only during the seizure and usually for a brief period afterward. Many have confused epilepsy with mental retardation, even mental illness. It is confirmed that epilepsy does not cause mental retardation.

2. A physician will diagnose and prescribe treatment. For most, seizures can be partially or totally controlled with properly administered medication. For some people with epilepsy, surgery can be performed.

3. When a person has a seizure, the first rule is to keep calm. The grand mal seizure, with arm flailing and jerky movements of the body, is what many

people think about when you mention epilepsy. However, there are many other kinds of seizures, some quite difficult to detect, which may only involve an eyeblink and short disturbance of attention. After a seizure has passed and the person is recovering, it is usually important to avoid causing embarrassment by making an issue of the seizure.

K. Mental Retardation

1. The definition of mental retardation presented by the American Association of Mental Deficiency (AAMD) in 1973 states: "Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviors and manifested during the developmental period."

2. Deficits in adaptive behavior are determined by measuring the personal independence and social responsibility expected for the individual's age and cultural group. During infancy and preschool years developmental milestones and sensorimotor skills are examined, while during the school years behavior is measured to a large extent, by school achievement.

3. Approximately three percent of the total population, six million people, will have I.Q. scores below 70. About five and one-half million will have I.Q. scores of 69 to 55, the remaining one-half million will have I.Q. scores of 54 and below.

L. Behavioral Disabilities

1. Some of the children may be difficult to manage in differing ways. At times they may seem to be just like the rest of us. Then, suddenly, a child with this disability may act in such a strange manner or say things which seem to be completely irrelevant to anything happening at the time that you may be taken off-guard. Or he may withdraw and refuse to communicate with you, perhaps even avoid eye contact. He may do things which are quite different than what is normally expected of another child of the same age. You might feel the child does things which are "bad." Yet these "bad" behaviors are part of his disability and it due to his disability that you will be working with him.

2. There is currently much controversy as to the cause or causes of behavioral disabilities with accompanying controversy about correct treatment or even if treatment is necessary. Some feel that behavioral disabilities are caused by abnormal functioning of the central nervous system with some of the more common references being minimal brain dysfunction, learning disabled, neurologically impaired or handicapped, hyperactive, emotionally disturbed, autistic, or hyperkinetic. Others feel this disability is caused by the child's environment, often placing the blame fully on the parents for their "poor parenting" of the child.

3. Recommended treatments are varied and include chemotherapy, dietary control, behavior modification, and psychological counseling of the parents. The proponents of each of these causes and treatments feel strongly that they have the answer. The families you serve are badly in need of answers to deal with the child's disability since it so often interferes with their lives socially, in addition to the child often

suffering socially and educationally. We all learn early that getting along with others is one of the most important facets necessary to live a full, productive life and you can be particularly useful to children with behavioral disabilities.

M. Syndromes

1. Occasionally you will hear a child's disability referred to as a syndrome. A syndrome is a group of signs or symptoms which occur together. The causes of syndromes come from many sources falling into general categories such as chromosomal, genetic, environmental, or unknown. We will give you a few examples of syndromes and the categories: genetic--tuberous sclerosis and Lowe syndrome; environmental--fetal alcohol syndrome and rubella syndrome; chromosomal--Turner syndrome and Down's syndrome; and for some the cause is unknown--Prader-Willi syndrome and Williams syndrome.

2. The most common pattern of chromosomal abnormality is Down's syndrome, which has an incidence of one in every six hundred to seven hundred newborns. The physical features are well recognized, so that the diagnosis is usually made at birth. The individual anatomical differences are for the most part not of much significance in themselves, but when a large number occur together in the same child an accurate diagnosis can be made. There are over one hundred different physical characteristics associated with Down's syndrome. The more common signs are mental retardation, short stature, muscle hypotonia, hyperflexibility of joints, round skull, small nose with low nasal bridge and prominent inner epicanthal folds, small ears, small curved little finger, a single crease in the palm, wide gap between first and second toes, and a defect of heart structure. Unusual chromosome distribution resulting in Down's syndrome is more likely to occur with older maternal age.

3. The level of functioning for Down's syndrome individuals has considerable variability. Recent developments in providing early stimulation and training to these infants have shown much promise for attaining functional levels that would not have been expected in the past. Education in the public school system can be adjusted to meet the needs and capabilities of Down's syndrome children.

4. This is only some of the specific information about some of the causes of the disabilities with which you may be working while providing respite care to families of children with handicapping conditions. You may have had some thoughts about how to do what is needed and expected, and how to know what to do with each individual child.

5. The best sources of information will be the child's parents and his siblings. Ask questions of the parents about any points which might be unclear to you. You and the parents might find it quite helpful for you to talk with the child's teachers, therapists, and/or physicians. Discuss this with the parents. If they feel it is appropriate they can make the necessary arrangements.

6. Perhaps you are beginning to feel that providing respite care is quite a personal thing. You are so right. In your care will be one of the most important things to these parents: their son or daughter who has unusual

needs to be filled by a select, caring group of human beings. Your service is badly needed and done well you will be rewarded with generous appreciation from the child's family.

7. Information on particular disabilities you might work with is important. Yet, so is knowledge of attitudes of those who have a disability.

N. Attitudes of Society Toward the Handicapped

We all have some built-in attitudes toward handicapped people. As members of a society our feelings about the different handicapping conditions are influenced by the people around us, and by the old stories that are passed down from one generation to the next. Several authors have described the changing attitudes of society toward its handicapped members. Looking back on the full span of human history it has been said that mankind has come through five major eras of thinking about and dealing with handicapped people. The stages are called; the Era of Extermination, the Era of Ridicule, the Era of Asylum, the Era of Education, and the Era of Occupational Adequacy. Although we believe we are now living in a sophisticated, enlightened age, we can still notice some remnants of the older attitudes from time to time.

O. The Era of Extermination

Destroying the disabled may have been justified for a very early society in which basic survival was always in danger. To limit the population to the available means of subsistence, primitive peoples killed the newborn who were deformed or diseased. In several primitive cultures defective children and very old people were left out in the wilderness to die because they could not contribute to the survival of the group. We should be aware of a similar attitude in our society when we hear of the withholding of lifesaving procedures from an infant who "will never be normal anyway."

P. The Era of Ridicule

The Age of Feudalism in Western Europe ranged from about 600 A.D. to 1200 A.D. In these times society consisted of freemen, serfs, and slaves. Nearly all were illiterate. Among the freemen, the landowners were the holders of wealth and power, and had leisure time for sport and amusement. For the peasant it was a time of hard labor and coarse pleasure. Superstition, witchcraft, myths, and monsters were part of the common understanding of all the people. Persons with physical deformity were living reminders of the elves, giants, goblins, and banshees which populated the medieval horror stories. The Era of Ridicule of the handicapped is gone, but still we can hear the echoes of those times as children call each other rude names on the playground and "sick humor" jokes are told by nightclub comedians. We are not far removed from the medieval baron who kept a dwarf as a jester and butt of his crude torment when we are entertained by monster movies.

Q. The Era of Asylum

The idea of providing places of shelter for the handicapped developed slowly during the Middle Ages in Europe. Two major movements helped the growth of a social conscience. First, the gradual shift from a simple agricultural society to one of trade and commerce produced a growth of wealth more widely distributed in the communities. The idea of providing care for the disabled expanded as the economic hardships of life became less. Second, the spread of the Roman Catholic religion across Europe promoted the attitude that the disabled were also children of God. Through the church a system of organized charity was highly developed. Every man who made a will left a sum to be distributed among the poor of his parish. Hospitals and asylums for incurables, for the poor, for orphans, for destitute travelers were numerous. Today we continue the attitude of sharing the care for the disabled people by supporting the United Way Fund, the American National Red Cross, the March of Dimes, and many other fund raising campaigns concerned with individual handicapping conditions. Throughout man's history we can see the general public attitude toward handicapped people follows the general pattern of economic well-being. In times of greatest stress upon a society to survive, very little concern is felt for the less capable members of that society.

R. The Era of Education

When the industrial revolution produces the need for more and better educated workers, the idea of training and education for a larger segment of the population became an accepted part of daily life. The hospitals and asylums which had been providing custodial care for the handicapped added some elements of education to their programs. The attitude of the people again slightly changed as the handicapped people demonstrated that with some training they too could be useful members of society. Education for basic skills of daily living allowed the handicapped to be less dependent on others for their care. Education for simple reading, writing, and arithmetic was just being started for the general population in the nineteenth century. A few teachers also included selected handicapped people in their classes. Edward Seguin and Maria Montessori are two pioneers in education for the mentally retarded. Other teachers followed their lead in providing an educational opportunity for the handicapped which continues to the present.

S. The Era of Occupational Adequacy

A recent emphasis on training for vocational success is another indication of society's changing attitude toward the handicapped. In the United States before 1920 several separate states had passed laws which provided funds to train disabled persons for employment. The first national law providing federal support to state governments to develop vocational training programs for disabled workers was passed in 1920. The 1940's saw a great variety of vocational training programs established by both private and government support. The Borden-LaFollete Act, 1943, The Vocational Rehabilitation Amendment, 1954, and the Vocational Act Amendments, 1968, and Section 504 of the Rehabilitation Act of 1973, are examples of national legislation that provide funding to develop vocational education and rehabilitation services. Although the great majority of handicapped persons can benefit from vocational training we must recognize that the public attitude toward handicapped persons will greatly affect their actual placement in gainful employment. The superstitions and prejudices of ancient times are not completely gone.

T. Who are the Handicapped?

The handicapped are the infants, the children, the adolescents, the young adults, and the old who have a life to live as we all do. There are some special needs to be taken care of; the following chapters will give you guidance in what to do. The handicapped members of our human family have always been with us, they always will be. Today we are better able to see that public concern and consciousness is directed toward providing the opportunities for life, liberty, and the pursuit of happiness available to ordinary citizens. Working as a respite provider you will be joining with a large and distinguished group of parents, teachers, physicians, therapists, and friends who are working together to help the handicapped live a life as close to normal as possible. Attitudes can be changed. You can help your relatives and friends to forget their stereotypes and prejudices and see each handicapped person as an individual.

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CHAPTER II: UNDERSTANDING FAMILY FEELINGS AND NEEDS OF THE HANDICAPPED

A. Parents Anticipate Having Normal, Healthy Children

All parents look forward to having a normal healthy child. All parents have their own ideas, hopes, and dreams for themselves and their children. Many people have said "my child will never do that," or "I'm going to do the same for my child as my parents did for me," or "I'm not going to treat my child that way." Parents have their own uniqueness, their own set of strengths, weaknesses, doubts, and determinations. Each of us is unique, having our own personality and temperament, having feelings of being "up or down" at different times, and of having problems.

B. Parental Reaction to a Handicapped Child

1. When parents find out that their child is handicapped they must rethink and change many of their plans and goals. Having a handicapped child is an unexpected source of stress and pain. Many times a parent is confused or insecure in this rethinking process and certain times in a child's development will be easier while at other times they will be more difficult.

2. Parent's reactions upon learning that their child is handicapped are varied. Periods of shock, bewilderment, and disbelief are common and immediate reactions. The intensity of the feelings of the family may vary according to the child's appearance, walk, speech, and other physical and mental abilities, as well as the amount of time, work, and expense involved in the care of the child. This shock, disbelief, and pain often makes some parents go from one expert to another searching for an authority to deny the condition. Others will hunt for someone to provide the "magic-cure." Still others push themselves and their child to work to "get over" the problem. After coming to grips with the problem and struggling with the pain, most parents, however, react in a realistic fashion and learn to cope and handle the problems and their feelings.

C. Emotional Reactions of Parents

Some feelings and reactions are natural and present at one time or another in most of the families of children with a handicapped condition. The more we understand this, the better we are able to understand the family. Typical emotional reactions by parents of a handicapped child are:

1. Anger: anger both at the spouse, the child, or themselves; anger also at the professional giving the diagnosis.

2. Grief: sorrow for themselves and the child; sadness for what was never realized and for the future of what may not be.

3. Fear and worry: fear of the unknown and worry about the future.

4. Confusion: not knowing what to do or expect; what is right or wrong, too little or too much information, too many decisions and a fear of making the wrong decision.

5. Guilt: rejection and denial, sometimes of the condition and sometimes of the child; guilt of the parents' involvement somehow in the cause of the condition.

6. Embarrassment: concern about what others think and how they will feel and act (or treat) the child and/or the parents.

7. Denial: denying the fact that the child is developmentally disabled; rejects the opinions and recommendations of the experts.

8. Blame: blaming themselves and others for the situation they find themselves in.

D. Making Adjustments

1. Regardless of the type of handicapping condition most families work out these feelings and begin to make adjustments. The length of time any given family needs to work out these issues certainly varies, depending on the strength of the family, the support the family receives, and the severity of the handicapping condition.

2. Besides the immediate family a respite care provider must also deal with peripheral family members such as grandparents, aunts, uncles, and brothers and sisters. The influences exerted upon the child and the family by these various family members are frequently significant and can have either positive or negative results. The respite provider must take into account the other family members. Especially important are interactions with the siblings of the handicapped individual. Jealousy, shame, and anger are all feelings that possibly will have to be handled. Again, ask the parents how to deal with the siblings.

3. The possibility of emotionally charged situations or encounters may occur within the family as well as with members of the extended family. Almost every family experiences feuds and fights, jealousies between some members, competitions, and emergencies. Being a witness to these encounters without getting personally involved or taking sides will challenge the best of respite care providers.

4. It is well to realize too, that persons of different ethnic backgrounds may have different cultural values, actions, reactions, procedures, or even goals, and ideals. When a person is working with a family of a different ethnic group or a different educational or economic group, it is necessary to learn more about the ways or expectations of the family based upon their culture. Careful observations of family interactions is the most productive way to learn about particular cultural or ethnic differences.

5. The main thing is to be aware of the child's and family's needs and expectations, their feelings and reactions, and how they want you to participate in the family. If there is one virtue demanded of a respite provider it is patience. Time and patience will very often bring solutions and at the very least, will provide the atmosphere that allows solutions. Avoid making decisions for the family. Try to learn how they want to handle a situation or a specific problem. The need to discuss mutual problems and interests is vital to a successful relationship between the

respite provider, the child who is served, and the family. Genuinely share concerns with the family and demonstrate this concern by your positive response to the family.

6. A benefit to parents from having a respite care provider is the prospect of being able to spend time away from their child for their own personal benefit. The habit of protectiveness of their handicapped child that parents have established is not easily broken. It is not uncommon for parents to grudgingly relinquish the responsibilities for care and concern that they have assumed over many years. The provider should recognize this feeling on the part of many parents and demonstrate an equal concern for the welfare of their child. Sharing their child with another person may be a difficult thing for parents to do, yet it is vitally necessary if the family is to be healthy and more nearly "normal" in the conduct of its members' activities.

7. Discipline is a very important subject and one in which much confusion and inconsistency is involved. No other matter of child care creates as many difficulties. Everyone has their own idea of what is adequate and necessary discipline for their children. Often the parents' decisions will be based on their own upbringing, personality, and culture. Few, if any, parents are always consistent in disciplining their children. But when there is inconsistency between the parents and/or the provider, there are bound to be problems. Healthy discipline is not punitive and it is important to discuss the range of discipline and the expectations for discipline of both the parent and the provider. The parents, naturally, have the final responsibility and decision, and different persons, especially from different cultures, have different interpretations of what is right and wrong.

8. Because of the wide variety of duties and expectations of the respite care provider there are many qualities that a parent may require of such a person. They include sensitivity, patience, and understanding, as well as qualities that indicate responsibility, commitment, good judgment, and social skills to relate well.

9. Throughout this chapter we have tried to emphasize that parents who have children with handicapping conditions are persons with many responsibilities. They want and need assistance with those responsibilities and problems and not to be blamed for everything concerning their child. Parents can be helped to bear the responsibilities, hurt, and anguish, and the best way to help a child is in cooperation with the child's parents. Parents need respite providers and assistance, but not just for business duties and emergencies, but also for fun, rest, and pure pleasure.

CHAPTER III: HOME AND SAFETY GUIDELINES

A. Introduction

1. Each year in the United States, one out of every three children is injured severely enough to require medical attention. During any one year "5,500 accidental deaths in children under five years of age occur in the home." (Vincent J. Fonlara, M.D. A Parent's Guide to Child Safety. (New York: Thomas Y. Cromwell Co., 1973), p. XX, Preface).

2. Accidents are a frequent cause of death or disability throughout the world, especially among children. The risk of accidents is increased if the individual is handicapped. Consequently, the respite care provider must have a knowledge of home safety and of the particular needs of the disabled person in order to effectively prevent accidents and care for the person. Many accidents are preventable with proper planning and attention.

B. Specific Objectives

1. The information in the checklist has two major implications for the respite care provider.

    a. First, you must know all the items on the list in order to provide safety for the handicapped person.

    b. Secondly, if parents know you have a sound knowledge of safety, it will help you develop a trusting relationship with the family.

2. Many persons do not leave their handicapped child with another person because they are afraid their child's unique needs may not be met. They are particularly concerned with their safety and physical care.

3. Parents will know when talking with you whether or not you are a reliable person to leave their child with by the questions you ask and the knowledge you display about safety. A good way to find out how a family cares for their child is to ask the parent to tell you what a usual daytime routine would be.

4. Be prepared by writing the resource telephone numbers you want on a sheet of paper. These are listed on the Safety Checklist. Rather than take the list with you, be familiar with its contents so you can ask questions. If you were to show up with a list in hand and start checking off the things that are wrong in the home, it would be very threatening to the parents. Instead, list the numbers of resources and have in mind safety factors. At a later time, after the parents have gone, you can make the environment even safer.

5. Learn all you can about the person's developmental skills and the way this particular family carries out their daily routine. An adolescent will sometimes need constant watching whereas a preschooler may not. It will depend on their individual development--whether they are crawling, walking, curious, or can read labels, etc. Activities must be planned for the skill level of the child if it is to be a safe environment.

6. Be observant; safety depends on your ability to see potential dangers and make necessary adjustments to prevent accidents.

7. When you visit a home for the first time, practice your observational skills. As you approach the home, notice all the items on the checklist which are outside. When you are shown the inside of the house, do the same observations in each room. This will help you plan and provide safe care when the parents leave their child in your care.

8. The adage "an ounce of prevention is worth a pound of cure" has never been more true than when you are taking the responsibility of caring for a handicapped person.

C. General Safety Guidelines

1. First Aid Kit

contents: Bandaids, Telfa, 1 inch bandage, hydrogen peroxide, tweezers, scissors, eye pad, thermometers (oral and rectal), 4x4 gauze, syrup of Ipecac

2. Phone Numbers (Emergency Community Resources)

Doctor ________

Where parents can be reached ________.

Police ________

Fire Department ________

Aid Car ________

Poison Control Center ________

Neighbors or relatives ________

Office Telephone/s ________

3. Exact address of where you are

4. Smoke Detectors and Fire Safety

-smoke detector may have flashing light if person is deaf
-child's interest in matches
-smokers in house
-plan for evacuation

5. Medicine Storage

-in locked cabinet or box
-all medicines should be labelled

6. All Electrical Cords

-in good repair
-in proper position

7. Electrical outlets--when not in use should be covered with dummy plugs.

8. Written instructions for any adaptive equipment in home.

9. A plan of action in case of fire or accident.

10. Where is fuse box located and how do you use it?

11. How do you shut off the water?

12. What do you use for emergency lighting?

13. Ask if there are any rooms where the child or person should not go unsupervised.

D. Specific Safety Guidelines--Inside

1. Kitchen

   a. Is child allowed in kitchen?

   b. If so, how much supervision is needed?

   c. Appliance safety --

      -are electric appliances disconnected from outlet when not in use?

      -are appliance cords out of child's reach?

   d. Stove

      -in good repair with supervised use at all times

      -is high chair at least 2 feet away from stove and any working surface?

      -are handles of pots and pans on stove turned out of the reach of children?

      -prevent from coming in contact with flames or burner

   e. Sharp knives and other sharp instruments kept out of reach of children or in locked drawer.

   f. Household cleaners stored in locked cabinet.

   g. Floor--clean and free from hazards such as upturned linoleum or clutter.

   h. Dishwashing Detergent--up out of reach or in a locked cabinet.

i. Hot beverages always attended.

j. Tablecloths out of reach of children.

2. Bathroom

a. What are person's normal toilet habits?

b. How much supervision and assistance does person need in bathroom?

c. Is a rubber mat placed in tub or shower?

d. Attend child every second while changing diapers.

e. Get instruction on any necessary adaptive equipment for bathroom.

f. Medicines and cleansing supplies kept in locked cabinet.

g. Dispose of diapers appropriately.

3. Bedroom

a. What are person's normal sleep habits?

b. Does person require special positioning for sleep?

c. Are side rails up on crib or other safeguards to prevent person from falling out of bed?

d. Are floors free of clutter?

e. Does person need assistance in changing clothes, getting into bed?

f. Does person take any special medications at bedtime?

g. Is there a convenient light switch for emergency night use?

h. Are dresser drawers always closed when not in use?

i. When a vaporizer is used, is it placed at a safe distance from crib or bed?

j. Use of pillow

4. Living Room

a. Are there any objects that might be harmful to person?

b. Do parents have specific rules of behavior for the living room?

c. Prevent child from playing with electrical cords (of lamps, stereo, T.V., etc.).

5. Basement

a. Is child allowed in basement?

b. Are tools, chemicals, cleansers, etc., kept out of persons's reach or locked up?

c. Is furnace in good working order?

d. Are all old newspapers and other flammable materials removed promptly from basement or storage area?

6. Fireplace

a. Does it have a fire guard or screen?

b. Are children supervised at all times when there is a fire going?

c. Are matches kept out of reach?

7. Utility Room

a. Are washer and dryer in good working order?

b. Are children allowed in this room?

c. Is the iron put away in proper place after use?

8. Garage

a. Is it free of clutter?

b. Are tools such as saws, nails, drills, etc., stored out of reach?

c. Is garage free of any potentially dangerous objects—are fertilizers, weed killers, paints out of reach?

9. Play Materials or Equipment for Indoors

a. Does the child enjoy playing with the toys?

b. Are the toys breakable and will they produce sharp edges?

c. Are toys put away when not in use?

d. Do stuffed animals and toys have detachable small parts that can be swallowed by small children?

e. Does the paint on surfaces that the child might chew on contain lead?

f. Are toys clean?

g. Do pencils, crayons and drawing materials have nontoxic labels?

h. Is child allowed to use scissors? If so, scissors must be blunt and short unless fine motor skills of the child allow use of pointed scissors. Scissors should open and close easily but grip paper firmly. Are scissors stored properly?

i. Are glues and pastes labelled non-toxic and specifying content and cautions?

j. Are there designated areas appropriate for specific play activities?

10. Stairs

a. nonskid surface

b. free of clutter (unobstructed)

c. do they have a handrail?

d. are they well lighted?

e. fence or guard for small children?

11. Walls

a. fireguards for stove and radiators

b. Are extension cords placed where they will not be tripped over?

c. Are drawers and cupboards closed when not in use?

12. Other Rooms

a. Is carpeting in good repair and fastened to floor?

b. Are edges of rugs prevented from curling up?

c. Are poisons kept in clearly marked containers, and are labels double checked before using?

E. Safety Guidelines--Outside

1. Yard

a. Free of trash, broken bottles, and other dangerous objects?

b. Child is supervised when playing outside.

2. Stairs

a. Are well lighted at night

b. Unobstructed

c. Have handrails

3. Fence

a. Gate is closed and locked when appropriate for safety of child.

b. Is in good repair, wood is painted?

4. Driveways and Roads

a. Keep free of toys

b. Children are not allowed to play in driveway or street.

5. Wheelchair Ramps

a. Are anchored securely at both ends.

b. Are free of clutter.

c. Incline is gradual.

6. Play Equipment—Jump Ropes

a. Handles of material that are not hard in case they come off.

b. Use only for jumping rope.

c. Trikes, wagons, bicycles and other wheeled toys:

- in good repair?
- wheels tight?
- seat secure?
- handle bar grips secure?
- adapted appropriately for physical ability of child?

d. Appropriate size for rider?

e. Stored in an accessible and safe area?

f. Edges of equipment are round or padded?

7. Pets

a. Is there a family pet?

b. Is child allergic to pet fur?

c. Is pet to be in or outside?

d. Are you responsible for care of family pet?

e. Be aware of animal hazards such as mouse poisons, flea collars, mouse traps, etc.

8. Car Safety

   a. Driver is licensed in Arizona and carries liability insurance.

   b. Car is maintained and in safe driving condition.

   c. Safety belts are on all adults and children before car is started.

   d. Approved car seats and beds are used for small children.

9. Fish Ponds

   a. Securely covered or drained.

10. Swimming Pool

   a. Secured by locked fence.

   b. Person must never be in pool area unattended.

F. Plants That Poison

Plant	Toxic Part	Symptoms
	House Plants	
Hyacinth, Narcissus Daffodil	Bulbs	Nausea, vomiting, diarrhea. May be fatal.
Oleander	All parts	Extremely poisonous. Affects the heart, produces severe digestive upset and has caused death.
Dieffenbachia (Dumb cane), Philodendron	All parts	Intense burning and irritation of the mouth and tongue. Death can occur if base of the tongue swells enough to block the air passage of the throat.
Rosary pea, Castor bean	Seeds	A single rosary pea seed has caused death. One or two castor bean seeds are near the lethal dose for adults.
Poinsettia	Leaves	Digestive upset, not as toxic as originally stated.
Mistletoe	All parts	Both children and adults have died from eating the berries.

Flower Garden Plants

Larkspur	Young plant, Seeds	Digestive upset, nervous excitement, depression, May be fatal.
Monkshood	Fleshy roots	Digestive upset and nervous excitement.
Autumn crocus, Star-of-Bethlehem	Bulbs	Vomiting and nervous excitement
Lily of-the-Valley	Leaves, Flowers	Irregular heart beat and pulse, usually accompanied by digestive upset and mental confusion.
Iris	Underground stems	Produces nausea, abdominal pain and vomiting.
Foxglove	Leaves	One of the sources of the drug digitalis, used to stimulate the heart. In large amounts, the active principals cause dangerously irregular heartbeat and pulse, digestive upset and mental confusion. May be fatal.
Bleeding heart	Foliage, Roots	May cause convulsions and difficult breathing when eaten in large quantities.
Sweet pea	Seeds	If eaten in large quantities can produce paralytic syndrome.

Vegetable Garden Plants

Rhubarb	Leaf blade	Large amounts of raw or cooked leaves can cause convulsions, coma, followed rapidly by death.
Potato	Sprouts, Foliage	Digestive upset. Fatalities have occurred.
Tomato	Leaves	Cardiac depression. May be fatal.

Ornamental Plants

Daphne	Berries	A few berries can kill a child.
Wisteria	Seeds, Pods	Mild to severe digestive

		upset.
Golden chain	Bean-like capsules in which the seeds are suspended	Severe poisoning. Excitement, staggering, convulsions, and coma. May be fatal.
Laurels, Rhododendron, Azaleas	All parts	Produces nausea and vomiting, depression, difficult breathing, prostration and coma. Fatalities have been reported.
Yew	Berries, Foliage	Foliage more toxic than berries. Death can occur suddenly in cases with severe intoxication.
Magnolia	Flowers	Headache and depression.

Trees and Shrubs

Wild and cultivated cherries	Twigs, Foliage	Contains a compound that releases cyanide when eaten. Gasping, excitement, and prostration are common symptoms that often appear within minutes. May be fatal.
Oaks	Foliage, Acorns	Affects kidneys gradually. Symptoms appear only after several days or weeks. Takes a large amount for posoning.
Elderberry	Shoots, Leaves Bark	Children have been poisoned by using pieces of the pithy stems for blowguns.
Black locust	Bark, Sprouts Foliage	Children have suffered nausea, weakness and depression after chewing the bark and seeds.
Holly	Berries	Vomiting and diarrhea. Has caused fatalities.
Mayapple	Apple, Foliage Roots	Contains at least 16 active toxic principals, primarily in the roots. Children often eat the apple with no ill effects, but several apples may cause diarrhea.
Skunk cabbage	Leaves, Rootstalk	Burning and swelling of mouth, tongue and throat.
Water hemlock	All parts	Violent and painful convulsions. A number of people have died from

		hemlock.
Buttercups	All parts	Irritant juices may severely injure the digestive system.
Nightshade	All parts, especially the unripe berry	Intense digestive disturbances and nervous symptoms.
Poison hemlock	All parts	Resembles a large wild carrot. Nausea, vomiting, and convulsions may occur. May be fatal.
Jimson weed (thorn apple)	All parts	Abnormal thirst, distorted sight delirium, incoherence, and coma. Has caused fatalities.

G. Some Pre-requisities for Accidents

a. Lack of planning.

b. Lack of attention to child and environment.

c. Hurry.

d. Inappropriate activities for skill level of child.

H. Summary

1. This checklist does not list all the possible dangers. Much will depend on the interaction of the child or adult with his environment. Emphasis has been placed on physical hazards which can be identified by observation and corrective measures will lessen the possibility of an accident occurring.

2. A child who is exploring his environment needs special and constant attention by the home aide to prevent burns, bumps, cuts, falls and drownings (bath tub). Some of the things which children drink or try to eat, at younger developmental ages are plants, medicines, tiny objects, cleaning products, cosmetics, pest killers and liquid fuels.

3. The home can be a safe place for children if you are alert to these typical household hazards and take a few simple precautions.

   a. Good observations of potential dangers and prevention measures taken.

   b. Knowledge of child's developmental level and skills.

   c. Continual and constant alertness to child and environment.

   d. Adequate planning.

   e. Schedule time needed for care and activities to avoid hurry or rush.

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CHAPTER IV: HEALTH MANAGEMENT

A. Administering Medications

1. Since many people who are handicapped receive one or more medications during the day, it is important to ask if the person for whom you are caring is getting medication.

2. It is also important to understand what the medication is, what it is for, and how it is given in order to feel confident about giving it. Medications can be in liquid form, given by spoon or dropper; some tablets can be chewed; other tablets can be crushed and mixed with food such as applesauce, jam, honey or mashed banana. Some tablets are coated and are intended to be swallowed whole and dissolved in the stomach. If someone holds a tablet in his mouth and drinks water at the same time he may swallow both without difficulty. Coated tablets are quite bitter if crushed or chewed in the mouth. However, a particular individual may require these to be crushed and mixed with honey or jam.

3. A demonstration by the parent of how the medication is to be prepared and given will help you to see how the parent approaches the handicapped person, and how easily the person accepts the medication. This will go a long way in making you feel at ease when it is time for you to give the medication.

4. Whether or not a demonstration is given, you should have the answers to the following questions before giving medication.

5. Does the person take medication? If so,

   a. what kind?

   b. what times?

   c. how is it given? (e.g., swallowed whole with water? crushed with food? are tablets chewable?)

   d. how easily does the person accept it?

   e. what is the medication expected to do?

   f. are there any side effects you should watch for?

   g. where is the medication to be kept?

6. Always approach the handicapped person with confidence and assume he or she will take the medication. A matter of fact approach to giving medication is usually successful. People who refuse medication usually do so if they sense that the one giving it is unsure of himself/herself.

7. If you carry personal medications, cigarettes, or other potentially harmful substances in your pockets or purse, always be sure they are not left where the handicapped person might find and ingest them. Ask the parent to suggest a safe place to store your purse, briefcase, coat, etc.

B. Detecting Illness in Handicapped People

1. The general signs and symptoms of illness in handicapped persons are:

    a. Any change in activity level or general behavior (listlessness, increased irritability, fussiness, loss of appetite).

    b. Any rash on face, neck, abdomen or back.

    c. Coughing, sneezing, red watery eyes, sore throat.

    d. Fever--if the person is hot to touch (using back of your hand), take his temperature with thermometer.

2. All of the above are generally symptoms of childhood communicable diseases, such as measles, mumps, chicken pox.

3. It is a good idea to ask parents how the person acts when not feeling well.

C. Procedures for Taking a Temperature

1. A person's normal temperature is not the same all day. It is always going up and down a little. It is usually slightly lower in the morning and higher in the late afternoon and evening. It is higher after the person has been running about. It may be up to 100. If you are taking the temperature by mouth, the mouth will be colder after a glass of cold water and hotter after a warm drink.

2. Up to 100 degrees the temperature may be due to illness or to general activity. A temperature of 101, however, probably means an illness whether the person has been rushing about or not.

3. It is important for you to know whether the person has his temperature taken by mouth, rectum, under the arm or in the groin.

4. In the mouth. Taking the temperature by mouth requires that the person is able to hold a thermometer in his mouth under his tongue with his lips closed and not bite it. This requires a degree of control which a good many handicapped people do not have. Do not take a temperature by mouth if the child has a seizure disorder. (If he had a seizure with the thermometer in his mouth, he would bite on the thermometer and break it in his mouth.)

5. To take a temperature by mouth:

    a. Read the thermometer. If it is not down below 95 give it a sharp shake. This can be difficult. Do it over something like a bed so that if you drop it, it will not break.

    b. Put the thermometer in the person's mouth, placing the silver bulb under his tongue and then close his mouth telling him not to bite.

    c. Leave the thermometer in the mouth for 2 minutes. Then read the temperature. Jot it down for the doctor.

d. Shake down the thermometer, wash it in cold water and replace it in its case.

e. When telling the doctor the temperature, tell him whether it was by mouth or some other part of the body.

6. To take a temperature under the arm or in the groin:

   a. Read the thermometer, making sure it is below 95. The thermometer is placed under the arm in the armpit or inside the leg in the groin for 2 minutes.

   b. This is slightly less accurate and the normal temperature is one degree lower than in the mouth.

7. To take a temperature in the rectum:

   a. This method gives the most accurate temperature and is used for babies and very handicapped people. The normal temperature is one degree higher than in the mouth.

   b. Again, shake the mercury down if necessary. Dip the thermometer bulb into cold cream or vaseline jelly.

   c. The best position for a small child is across your knee or with the bigger child lying on his side, with the knees drawn up. Do not try to do it with the child lying on the bed on his tummy or back. Slip the bulb gently into the rectum (about one inch), reassuring the child as you do it. Steady the thermometer lightly between your fingers. Leave it in for one minute.

   d. If the person has a fever, temperatures should be taken at least every 4 hours. If the temperature is over 102 degrees take every 2 hours. The person can be given a cool water or alcohol sponge bath. Do not give aspirin unless the parent or physician has given permission and dosage.

   e. If the fever persists longer than 24 hours or increases above 101 degrees notify the parent or doctor.

   f. IT IS IMPORTANT TO DETERMINE WITH PARENT IF IT IS THE RESPITE CARE PROVIDER'S RESPONSIBILITY TO CALL THE PHYSICIAN DIRECTLY, OR WHETHER HE IS ONLY TO CALL THE PARENT WHO WILL THEN OBTAIN MEDICAL ADVICE. IF IT IS YOUR RESPONSIBILITY, BE SURE YOU HAVE MEDICAL INSURANCE INFORMATION AND WRITTEN INSTRUCTIONS FROM THE PARENT AUTHORIZING YOU TO SEEK HELP ON THEIR BEHALF.

D. General Caring for Handicapped Persons During Illness

1. Follow instructions from parent or physician. These should include:

   a. Type of food person should eat—if different from usual diet.

   b. Amount and types of fluids person should drink—frequently handicapped persons with a fever become dehydrated unless given adequate amounts of liquids.

c. Amount of rest needed--usually people should be allowed to rest or play quietly until they are without a fever for 24 hours.

d. Observations by respite care providers--looking for increased drowsiness, fussiness, seizures (many persons will have seizures with high temperatures). Some handicapped persons may not have enough speech to be able to talk about how they feel. For these individuals, the respite care provider's observations are particularly important.

E. Specific Problems of Handicapped Persons and What to do About Them

1. Seizures:

a. Keep calm! The most important thing is to protect the person from bodily injury. Stay with the person!

b. Place the person on the floor, do not restrain movement.

c. Try to support the head, gently turning it to the side with face downward so that mucous and secretions will run out to prevent choking.

d. If airway is clear (i.e., person is breathing easily) and more particularly if jaws are clenched, do not force anything between the teeth.

e. Loosen clothing around the neck.

f. Allow person to rest quietly and become fully conscious before encouraging regular activities. While resting, the person should be placed on his side with face downwards. (Especially if vomiting occurs.) Observe frequently to see that the person is breathing easily and that there is no bluish tinge to the skin, indicating that he or she is not getting enough air into the lungs.

g. If a series of seizures occur before the person has fully gained consciousness call the aid car immediately!

h. Keep the following record of each seizure which occurs while the parents are not at home. This can be helpful to the physician:

Time seizure started: __________

Terminated: __________

Duration: __________

Describe brief activity before seizure: Cry preceded:

yes_____ no_____

____

____

____

Change in person's behavior after seizure:

Weakness, general _____

Weakness on one side _____

Vomiting _____

Unable to walk _____

Sleepy _____

Unable to talk _____

Unable to see _____

2. Lung Congestion

This frequently occurs with handicapped persons who are so handicapped that they do not have enough muscle strength to cough up mucous from the lungs. When these people get colds, even more mucous stays in the lungs. They need special positioning to help them raise the mucous from their lungs. This positioning is call Postural Drainage.

a. Postural Drainage:

i. Remove all tight clothing.

ii. Place person on floor on pad or blanket with pillows to support body.

iii. For a small child, it is best done with the child placed on a pillow over the home aide's knees.

iv. The person is placed in the follwing positions to drain the lungs for 3 to 5 minutes in each position:

(1) Person placed on right side to drain left side of lungs.

(2) Person placed on back to drain front of lungs

(3) Person placed on left side to drain right side of lungs

(4) Person placed on abdomen to drain back of lungs.

(5) Place the hand on the person's front, side or back, press lightly, and vibrate to help loosen mucous.

3. Abdominal Pain

a. Have the person lie down.

b. Do not give any medication.

c. Take the person's temperature.

d. Reassure the person.

e. If the pain does not subside, is severe, or the person has a temperature, consult the physician.

4. Vomiting (Nausea)

a. Have the person lie down.

b. The person should have nothing to eat or drink until the nausea or vomiting has passed.

c. Call parent to physician if condition continues over 24 hours or person has elevated temperature or other symptoms such as a rash.

d. A cool wet cloth may be applied to the face to comfort the individual.

5. Diarrhea

a. Allow person to sit quietly or lie down in a room near a bathroom.

b. Give nothing to eat or drink for 4 hours, give only clear liquids for 24 hours (water, jello, apple juice, ginger ale), and no milk products, then to feed bland foods for 48 hours. Bland foods include applesauce, bananas, sherbet.

c. Call parents or physician if the diarrhea persists longer than 24 hours.

6. Headache

a. Have the person lie down in a quiet place.

b. Take the person's temperature.

c. Give no medication.

d. A cool cloth applied to the head may relieve discomfort.

e. Call parent or physician if headache is severe, persists over 24 hours, or recurrent, or if temperature is over 100 degrees.

f. Headaches may be indicative of some acute or chronic illness or physical condition that requires a remedy.

7. Menstrual Discomfort

a. Reassure teenager.

b. Handicapped teen may need help with own hygiene.

c. For mild cramps, encourage regular activities.

   d. For severe cramps, a short period of quiet rest enables many girls to carry on their regular activities.

   e. A few may need to rest if the pain persists or if bleeding is heavy.

   f. If severe cramps occur repeatedly, advise the parents to seek medical consultation.

   g. Give no medication, including no aspirin, unless parents have left medication for this purpose.

8. Accident and Emergency Procedures

   a. Accident and emergency procedures for handicapped persons are basically the same as for other children with the addition of a few special considerations in case of poisoning, fractures, and choking.

9. Poisoning

   a. Follow the procedure as stated in the Red Cross First Aid Manual.

   b. In addition to reporting the substance the person may have swallowed, it is important to report any medication the person is receiving so that the combined effect of the poison and medication can be determined. As a result of this combined action, there may be additional side effects to which the respite care provider should be alerted.

10. Fractures

   a. When trying to splint a fracture on a person with cerebral palsy or any condition affecting the muscles, it is important not to force an arm or leg into any position it does not go easily.

11. Choking

   a. Follow the instructions in the Red Cross Standard First Aid Manual.

   b. Because of low muscle strength, some handicapped persons may choke easily and frequently.

   c. Choking is frightening, but do not worry as long as the person's color is normal. A person who is choking needs an adult standing by to give assistance, but do nothing more unless the person becomes unable to breathe or cough.

F. Some Questions to Ask Parents

1. Medications:

   a. Does the person receive medication?

      i. What kind?

ii. What times?

iii. How is it prepared and given?

iv. How easily does the person take it?

v. What is the medication expected to do?

vi. Are there any side effects the respite care provider should watch for?

vii. Where is the medication kept?

2. Illness:

   1. How does the individual act when he is sick? (irritable? listless? fussy?)

   2. How is his temperature taken (oral? rectal? axillary?)

   3. Is he given aspirin for a fever? If so, what dosage? How is it prepared and given? (mixed with applesauce? juice? or a chewable tablet?)

   4. Where is the thermometer kept?

3. Accidents and Emergencies

   a. Does the person have seizures? How often?

   b. What do you do for him during and after a seizure?

   c. How does he act after a seizure? (sleepy? active?)

   d. What is doctor's name and phone number? What is the medical insurance information the respite care provider needs in care of emergency?

   e. Which emergency facility does family use?

   f. What is the family's exact address and phone number?

   g. What is name and phone number of closest neighbor? Do parents want the respite care provider to call them first if child is ill? or to call the doctor? or neighbor?

G. Medication Resource Information (Drugs)

1. Clanazepan or Clonopin

   a. USES: a tranquilizer, similar to Valium, induces calming effects, central nervous system depressant, may be used alone or as an adjunct, in the treatment of seizure disorders. Clonopin is useful in the treatment of petit mal seizures. It decreases the frequency, severity, and duration of petit mal seizures.

b. WARNING: abrupt withdrawal may cause seizures so gradual withdrawal is essential especially with patients that have been on this drug for a length of time. Some drugs potentiate the action of Clonopin such as narcotics, barbituates, Phenobarbital, and antidepressants. Precautions should should be taken if it is in combined use with other anticonvulsant drugs.

c. ADVERSE REACTIONS: increased salivation, skin rash, drowsiness, ataxia, confusion, slurred speech, possibility of muscle weakness and palpitations. Also may have opposite effects of what it is supposed to do such as an increased amount of activity, restlessness, and glassy eyed appearance.

d. USE FOR CHILDREN: used in the treatment of petit mal seizures, it may be used as the sole treatment for petit mal seizures but if another kind of seizure disorder exists it may be used adjunct to other anticonvulsant drugs. The extra benefit of Clonopin is that it may be used in infants.

e. OVERDOSE: restlessness, confusion, coma, diminished reflexes, and death. Make the child vomit, check the amount taken, and report to the doctor.

2. Dilantin

a. USE: an anticonvulsant drug useful in the treatment of epilepsy. Acts primarily on the motor cortex of the brain where spread of seizures activity can be inhibited.

b. WARNING: abrupt withdrawal may precipitate seizures. Reduce gradually.

c. ADVERSE REACTIONS: most common are dizziness, insomnia, nausea, vomiting, motor twitching, constipation, rash, and infected gums.

d. USE FOR CHILDREN: anticonvulsant drug that controls grand mal seizures but not petit mal seizures, therefore if both conditions are present, combined therapy is required.

e. OVERDOSE: if overdose is taken Dilantin can cause diminishing reflexes of respiratory, central nervous system, and cardiovascular system. Coma and death. Make the child vomit, check amount taken, and notify the doctor immediately.

3. Mellaril

a. USE: Mellaril is a not highly potent tranquillizer used frequently for it has few side effects. Used to relieve anxiety-tension states, agitation, hypermobility, abnormal initiative and behavioral problems. If may be used in adjunct to anticonvulsant drugs.

b. WARNING: this drug can potentiate central nervous system depressants and alcohol. It is not used in children under the age of two. When drug is discontinued signs of the patient's problem can reappear within a week or so.

c. ADVERSE REACTIONS: there are minimal side effects with this drug and that is what makes it so good. Main problem would be drowsiness, other possibilities would be dry mouth, skin rash, or tremors.

d. USE IN CHILDREN: Mellaril is used in treatment of behavioral problems, control of hyperactivity, agressiveness, relief of neurotic depressive reactions.

e. OVERDOSE: if overdose is taken Mellaril can cause coma, diminished reflexes, and death. Make the child vomit, check amount of the drug taken, and report to the doctor.

4. Ritalin

a. USE: useful in the treatment of M.B.D. children. It is a stimulant and acts on the central nervous system. It improves the mood and counteracts lethargy and lassitude. Also used in depression, apathetic, and withdrawn type behavior cases.

b. WARNING: not to be used in children under the age of 6 years. May lower the convulsive threshold in patients with a history of seizures.

c. ADVERSE REACTIONS: increased activity, nervousness, insomnia, skin rash, nausea, dizziness, tachycardia, loss of appetite, and weight loss.

d. USE FOR CHILDREN: M.B.D. children, not to be given under the age of 6 years, given with caution to children with seizures or epilepsy.

e. OVERDOSE: vomiting, agitation, tremors, overly excited, muscle twitching, convulsions, tachycardia, and finally coma. If ingested make the child vomit, take note of how many taken and when, notify doctor.

5. Stelazine

a. USE: Stelazine is a potent mood elevator, used in management of pyschotic disorders. It controls excessive anxiety, tension, and agitation. Frequently used in cases of withdrawn patients or those who have delusions and hallucinations.

b. WARNING: this drug may impair mental and physical abilities especially the first few days of therapy. It can potentiate central nervous system depressants and alcohol. Not given to children under the age of six. When drug is discontinued signs of the patient's problems may reappear within a week or so.

c. ADVERSE REACTIONS: drowsiness, dizziness, skin rash, dry mouth, muscle weakness, blurred or double vision, tremors, shuffling gate, spastic contractions of various muscles of neck, face, and back. These would occur more often in the patients who have been on this drug for a long period.

d. USE IN CHILDREN: Stelazine is used in behavioral problems involving hallucinations, delusions, or withdrawn symptoms.

e. OVERDOSE: if overdose is taken Stelazine can cause coma, diminished reflexes, and death. Make the child vomit, check the amount of drug taken, and report to the doctor.

6. Valium or Diazepam

a. USES: Valium is a tranquilizer that induces calming effects, it is a central nervous system depressant, used for relief of tension and anxiety states. May also be used as adjunct for relief of skeletal muscle spasms in convulsive disorders. Never used as the sole therapy for seizures.

b. WARNING: As with other agents which have anticonvulsant activity when Valium is used as an adjunct in treating convulsive disorders, the possibility of an increase in the frequency and/or severity of grand mal seizures may require an increase in the dosage of an anticonvulsant medicine. Abrupt withdrawal may cause temporary increase in frequency and/or severity of seizures. Precautions should be taken if Valium is combined with other anticonvulsant drugs. Careful consideration to the pharmacology of the two drugs used should be given since some drugs potentiate the action of Valium. These include narcotics, barbiturates, Phenobarbital, and antidepressants. Because of varied responses to central nervous system acting drugs therapy should begin with the lowest dose and be increased as required.

c. ADVERSE REACTIONS: drowsiness, fatigue, ataxia, confusion, constipation, changes in salivation, skin rash, and tremors.

d. USE FOR CHILDREN: Valium is frequently used in adjunct with other drugs to treat convulsive disorders. Never used as the sole treatment and not to be given to children under the age of 6 months.

e. OVERDOSE: restlessness, confusion, coma, diminished reflexes, and death. Make the child vomit, check amount of drug taken, and report to doctor.

CHAPTER V: BEHAVIOR MANAGEMENT FOR THE HANDICAPPED

A. Problem Behavior

1. Some individuals have behavior problems. They misbehave. This may cause numerous problems, including fear on the parents' part to take their child on out-of-home activities, unpleasant and angry interactions between the child and parents, and difficulty in finding people to care for the handicapped individuals. Attempting to handle behavior problems can be a difficult and confusing process at times. However, applying some basic principles of behavior management can make this process much easier. This chapter will present some ideas that parents, teachers, and professionals have found particularly useful in increasing desirable behaviors, decreasing undesirable behaviors, and developing more satisfying relationships with individuals.

2. The first rule to remember is that the individual is a person and just because there are some bad behaviors does not mean the person is a bad person. Handicapped people are people; they all have emotions and feelings just like everybody else. Sometimes they have difficulty in expressing their feelings. By our caring about them as individuals, liking them, and following some basic techniques, behavior problems should be fairly easy to handle. Handicapped individuals are likely to initially respond in varying ways to the behavioral management techniques that are presented here. Some individuals may even resist. Autistic individuals, for instance, are particularly difficult, and both the parent and the respite provider must keep in mind that even one very small piece of lasting progress is indeed something worth shouting about. All of the procedures described in this chapter are presented only to enable the respite provider to better handle the individual as the parents want their child handled. Respite providers are not expected to be parent trainers. Also, while the respite provider should not use any techniques that the parents do not approve of, you should feel free to discuss with the parents procedures you do not feel comfortable using. Hopefully you, the respite provider, and the parents will be able to mutually agree on positive procedures to use for behavior problems.

3. To illustrate a number of the ideas that will be presented, one particular case will be used. Dennis, an 11-1/2 year old autistic boy, has had numerous problems including running away, stealing food from stores, spitting, kicking, and cursing. After many months of concentrated work by his parent and respite provider, Dennis has fewer undesirable behaviors, and has learned many new appropriate behaviors. Although he still wanders away at times, the parent and respite provider no longer worry about his being arrested for pilfering things or resisting authority.

B. Rule Setting

1. Rule setting is a very important concept, and is the first step in developing effective behavior management skills. Setting clear rules will establish what behaviors are acceptable and what behaviors are unacceptable in a given situation. It is important for the individual to know what he can and cannot do, so that he has the opportunity to behave appropriately.

2. Most families do have rules, and it will be the respite provider's responsibility to become familiar with those rules. However, the respite provider will also be responsible for developing new rules when necessary in conjunction with the parents. Once the respite provider and the parent have agreed on specific rules these rules can be clearly presented to the handicapped individual. Making lists of the rules in writing is usually a good practice, as it usually can save an argument or other problems later. But the major consideration should be that the rules are clear, understood by all, and consistently enforced. Once the rules have been set, consequences must be provided for the individual's behavior. By providing certain types of consequences, appropriate behavior can be increased, and undesirable behavior may be decreased.

3. As an example, many rules were set for Dennis. His parent had specific expectations for his behavior, and she and the respite provider spent time discussing these and coming up with a number of clearly stated rules. An area of concern was assigning Dennis certain daily chores. The respite provider drew up a list of the chores which were Dennis's responsibility. This list was presented to and discussed with Dennis. Some of the rules involved putting away his clothes, setting the table before meals, and collecting and taking out the garbage. Other rules were also made for Dennis, including paying for any food taken at the store, not spitting, and not cursing when he was picked up. Dennis's parent and respite provider also developed a list of consequences applied when the rules were not followed or broken. These consequences were also clearly stated so that Dennis knew exactly what to expect.

4. Consequences are very important to rule setting and behavior management. Basically, people learn how to behave depending upon the consequences they receive from their behavior. There are two types of consequences which are most effective: 1) positive reinforcement, which increases desirable behavior, and 2) punishment, which decreases undesirable behavior. Learning to use consequences in a systematic way is a skill that all respite providers will need in dealing with children with behavior problems.

C. Increasing Desirable Behavior

1. Positive reinforcement increases desirable behavior. Many things can be positive reinforcers: attention, praise, privileges, candy, money, or anything that a particular individual enjoys. These positive reinforcers are given to an individual when the individual follows rules that have been set, or does anything that is appropriate or pleasing. Reinforcers tell the individual that he/she has done well and that the behavior was pleasing, and they encourage further desirable behaviors. When good behaviors are reinforced, they occur more frequently.

2. While reinforcement is a fairly simple and straightforward procedure, care must be taken when choosing reinforcements to choose things that the child likes. Not all individuals will repond the same to all reinforcements. For example, one person may respond positively to being allowed to play outside a half hour longer than usual, while another person might not consider that so desirable. If the reinforcer you choose for the individual is not important or undesirable to that person, the process is

not likely to be successful. When choosing reinforcers for an individual's behavior, it is usually a good idea to ask the person what he/she likes and give him/her a say in this decision. This way, there is less risk of choosing an inappropriate reinforcer. However, the only true way to tell is a reinforcer is effective is to observe its effect on the person. If the desired behaviors occur more frequently, the reinforcer has been effective. If not, then the reinforcer may not be appropriate and some other may need to be selected. Reinforcers must also be things you can give. This means that you are physically able to give (smiles, free time, words, toys, food) and that you feel good about giving. If you cannot give the thing, for example sunshine or snow, you cannot use it as a reinforcer. Or, if you do not believe in giving something—if it makes you feel bad when you give it, that probably will not be a good reinforcer.

3. Another important consideration in using reinforcement is when to reinforce a behavior. Generally, reinforcement is most effective when the reinforcer is given immediately after the individual has done something desirable. If the reinforcement is not given quickly and the person has to wait to receive it, the effect may not be strong enough to encourage continued desirable behavior. When reinforcement is given quickly, the person learns that he has done something good, and that he is appreciated. Also, when attempting to develop and increase a new behavior, reinforce the person each time the behavior occurs until that behavior becomes strongly established. Once the behavior has become well established and occurs regularly at the appropriate times, there is no need to continually reinforce it each time. At this point, the program should change to reinforcing the good behavior maybe once every other time, and then perhaps less frequently, but enough to let the child know that what he is doing is well. Giving less frequent reinforcement over time will help to make the good behavior a stronger and more long-lasting response. In natural events, people are not always reinforced for doing something good, but every once in a while people are reinforced, which is enough to keep them doing the good things they do. This approximation of the natural environment is the ultimate goal of any behavior management program.

4. A goal of any behavior management program using positive reinforcement is to have social reinforcers become the most effective reinforcers. Social reinforcements are reinforcements that have to do with personal contact. The most effective social reinforcers are praise and positive attention. All people enjoy praise and positive attention. Simply stated, it makes them feel good about themselves and the people who give the praise. With behavior problem individuals, however, praise and attention are sometimes not enough. Some people do not view praise as a positive reinforcer and consequently will not work to get it. With such individuals, more obvious reinforcers will need to be used, such as food, candy, money, or some desired toy. It is often necessary to start a reinforcement program with those obvious reinforcers; be sure to always pair those with social reinforcers. This helps the individual to learn that praise and attention are good things too, and are things to be sought after. An example may help to illustrate this point:

> Robert, a seven year old boy with a seizure disorder, was mostly uncontrollable at home. He refused to do anything his parents requested, and fought with them frequently. A behavior management

> program was instituted with Robert and his parents. It was decided to give Robert one of his favorite cookies each time he did what his parents asked, and to simultaneously praise him by telling him how good he was, how proud his parents were of him, and to give him a hug. With this procedure, Robert's negative behavior decreased greatly and he began to do what his parents asked without fighting. The parents gradually stopped giving him cookies each time, but continued to heap on the praise, which Robert now seems to enjoy immensely. Robert's behavior has improved steadily, and he enjoys pleasing his parents as much as receiving their praise and attention.

5. The point to emphasize is that in any use of positive reinforcement of good behavior, the goal should be to use social reinforcement whenever possible. When other reinforcers are necessary, always combine them with praise and attention and gradually decrease the use of the other reinforcer when possible.

6. Point systems offer another alternative way of reinforcing behavior. This is a way of delaying the chosen reinforcement until a certain goal is reached. In a point or token system, the person must earn a certain number of points to attain his reinforcement. Either the respite provider or the parent gives points for the appropriate behaviors or whenever the individual follows the rules that have been set. Each time a point is earned, this should be paired with praise and attention. These points are then totaled and saved until the individual has earned enough to gain the reinforcer decided upon. When using a point or token system, the goal must be clearly specified to the person, and the exact number of points necessary to earn that goal must be clear to all. For example, a child might choose staying up a half hour later at night to watch TV as a reinforcer. To attain this, a system is designed whereby the child must earn 10 points a day to obtain the reinforcement, for example, by carrying out his chores at home and playing with other children without fighting. The reinforcer is given only if the child earns his 10 points. If not, he goes to bed at the regular time. Again, when using such a point system, remember to always reinforce desirable behaviors with praise and attention when giving the points.

   An example from Dennis's program should help to illustrate the use of positive reinforcement:

> When Dennis was taken shopping, he would take things off the store shelves and eat them while his mother or respite provider was shopping. He especially enjoyed dried packaged cereals. While this was one of his favorite things to do, one of his least favorite was doing his chores without a battle. His mother and respite provider developed a list of certain daily chores that Dennis had to perform and for which he could earn a certain sum of money. The respite provider made a list of these chores and the money to be earned for each. Putting away clothes earned 1¢, setting the table earned 2¢, and collecting and taking out the garbage earned 5¢, and so on. An itemized list was kept for each day, and as each chore was accomplished Dennis was allowed to mark the amount earned on the list. Dennis then received the total chore money earned at the end of the day, and the money was deposited in the bank (a glass peanut butter

jar so that he could see the money pile up!). Dennis was escorted to the store regularly by the respite provider to price a particular thing he wanted to save for, and when he earned enough money a special trip was made to the store so that he could purchase his treat. Dennis is praised as consistently as he earns his money and treats also. Since his program was begun, Dennis performs his chores, and no longer takes food from the store without paying.

D. Decreasing Undesirable Behavior

1. Most individuals behave inappropriately or in some undesirable way at one time or another. Individuals with developmental disabilities are subject to these same transgressions to varying degrees. Some developmentally disabled people have many behavior problems, such as Dennis does, and others may have few; but respite providers are likely to encounter situations in which they have to deal with the child's inappropriate behavior. Several behavioral management techniques can be very effective when used consistently and systematically.

2. Punishment is used frequently to deal with undesirable behavior. Some forms of punishment are effective and long-lasting, such as extinction and time-out, which will be discussed later; and some forms of punishment are not so effective and can create more problems, such as physical punishment. Physical punishment may suppress undesirable behavior, but it can also have several negative side effects. An individual who is punished physically may become fearful of adults, or may lie to avoid punishment, and only suppress the undesirable behavior in the presence of the person who punishes him. Also, the effectiveness of physical punishment is often temporary and when the effects wear off the individual may return to the undesirable behavior. Physical punishment rarely brings about the desired changes and it can, and often does, backfire with negative effects. Whenever possible, avoid using physical punishment. As a respite provider, it is important to remember that any form of punishment used must be discussed with the parent and agreed upon before it is used.

3. As we mentioned earlier, there are effective forms of punishment which will decrease unacceptable behaviors without the potential negative side effects of physical punishment. One of these methods is called extinction. Extinction is essentially the opposite of reinforcement: non-reinforcement! If a behavior is not reinforced, the behavior will eventually disappear and the person will no longer engage in it. Inappropriate behavior is often attention seeking, and ignoring that behavior is helpful in eliminating it. Ignoring is the key word. Ignore inappropriate and undesirable behavior by not paying attention to it or not reinforcing it in any way. Extinction can be used in many situations, and any behavior that does not threaten the well-being of the individual or others can be ignored.

4. Trying to ignore very annoying behaviors is indeed a difficult task. This is especially true when the extinction process is just begun. When extinction is used, there is often an increase in the intensity of the undesirable behavior as the person will try harder and harder to get the reaction he desires. However, these undesirable behaviors will indeed decrease if they are consistently ignored over time. Extinction will be

most effective when used together with positive reinforcement. Ignoring undesirable behavior while positively reinforcing appropriate behavior is one of the best ways of eliminating inappropriate behavior. The classic example of extinction procedures is temper tantrum control. When a person wants something which he cannot have and begins to cry, scream, pout, and try to make a parent or respite provider uncomfortable enough to give in to his demands, consistently ignoring these behaviors will show the individual that they are not effective ways of getting his way. But while ignoring such inappropriate behavior, always be alert for positive behaviors to reinforce.

5. Another method of handling undesirable behavior is called "time-out." Time-out is an especially useful technique with undesirable behavior which is difficult or impossible to ignore, such as self-destructive behavior or fighting. Time-out means time out from reinforcement, and essentially involves removing the person from a situation in which he is engaging in undesirable behavior and receiving reinforcement for it. For example, a person may be teasing and harassing other individuals when they are playing a game. Everyone is upset and are trying to make the instigator stop. Obviously, the respite provider could ignore this behavior but the individuals are reinforcing the "trouble-maker" by getting upset, which is his desired goal. Time-out used in a situation such as this can be as simple as sending a person to his room, which removes him from the reinforcing situation. To use time-out, the individual should be put in his room or someplace that is dull and nondistracting whenever he misbehaves and it cannot be ignored. Tell the person exactly why he is being put in time-out and for how long. Time-out periods should be short (5 to 10 minutes), allowing the individual to gain some control over himself and think about the situation which led up to the time-out. Avoid discussions and arguments with the child about reasons why he is being sent or the amount of time selected for time-out. Also, it usually is a good idea to tell the person that additional time will be added if he leaves early or creates a disturbance which cannot be ignored. Be specific about additional amounts of time!

6. Remember, when using the time-out method, non-reinforcement is the order of the day!

> Dennis engages in behaviors such as kicking and spitting which are difficult to ignore, and time-out procedures are used. He has made a real hassle out of time-out for the parent and respite provider by creating disturbances and arguing about how much time has elapsed. Engaging in these arguments was similarly reinforcing for Dennis, so the respite provider and parent decided to use a mechanical timer (a kitchen timer) to keep track of the time-out period, and have successfully freed themselves from any interaction with Dennis for the entire length of the time-out period.

Both extinction and time-out are quite effective, but they cannot be used in isolation. Always try to combine these techniques with positive reinforcement of appropriate behavior, and have the parents agree with the punishments selected. One reason people engage in undesirable behavior is because they do not know what desirable behaviors can take its place. This can be done when rules are being set, after an inappropriate behavior has been ignored, or after a time-out has been completed. It is important to always provide the person alternative ways of behaving that will lead to positive reinforcement, and then to reinforce these behaviors whenever they occur.

7. One other form of decreasing undesirable behavior should be considered. If a behavioral management program is set up which involves the earning of points, money, privileges, or other tangible objects, these reinforcers can be taken away for inappropriate behaviors as easily as they can be given for good behavior. For example, Dennis earns money for doing the chores mentioned previously. However, when he does certain inappropriate things, such as pouring all the laundry detergent into a sink full of water to play in, specific sums of money are subtracted from his bank. Similar systems can be accompanied with points; subtracting points for undesirable behavior as well as giving them for good behavior. This type of program is easily set up, but care must be taken to specifically spell out any penalities before the program is begun.

8. In summary, when attempting to increase desirable behaviors and decrease undesirable behaviors, several important steps must be considered:

   a. Set rules that are clear and specific, and then follow them consistently and uniformly. Rules can be changed or new rules set at any time during the program, as long as they are clearly understood by all.

   b. Observe the individual's behavior closely to identify both the desirable and undesirable behaviors.

   c. Select the specific behaviors (target behaviors) that are to be increased or decreased.

   d. Identify which events lead to these behaviors, what consequences maintain these behaviors, and what desirable behaviors can replace undesirable behaviors.

   e. Choose appropriate positive reinforcements for the individual.

   f. Positively reinforce any and all desirable behaviors the person shows as quickly as possible, always remembering to give them a good deal of praise and affection.

   g. Use extinction, time-out, and loss of reinforcers to decrease undesirable behavior, and avoid the use of physical punishment whenever possible.

   h. Be consistent and follow through at all times with the positive and negative consequences chosen.

9. It is important to remember that changes will not occur over night. Changing behavior takes time and a good deal of patience. Also, it takes a certain amount of persistence. Keep in mind that your expectations for change must be realistic, and allow for the process to take time. One other point deserves mention. Individuals respond best to positive

consequences and receiving good feedback on their behavior. Consequently, any behavior management program should attempt to be mostly positive in nature. Reinforcing good behaviors is more effective than punishing undesirable ones. When planning any program, emphasize positive behavior and positive reinforcement, and only use punishment techniques when absolutely necessary.

10. Several other procedures will prove helpful when attempting to increase desirable behaviors and decrease undesirable behaviors. Successful behavior management is dependent upon being a good observer of behavior. A tool the respite provider can use to help keep track of what is happening in the program is to chart those behaviors which are of concern. "Charting" involves keeping a record of exactly how many times the child does the desired or undesired behavior (target behavior). For example, if a person has many temper tantrums, and the behavior management program implemented focuses on these, a chart can then be kept to show how many tantrums the person has each day, and whether or not they increase or decrease. To illustrate, see Chart 1 at the end of this Chapter.

11. As can be seen in Chart 1, over the course of two weeks this child's temper tantrums became non-existent when an extinction program was used, and alternative positive behaviors were provided and reinforced. The chart itself has several advantages. It clearly shows that the extinction process was very effective. Although a respite provider would probably have been able to note this without the chart, the chart makes it obvious and dramatic. Also, keeping the chart lets the person see exactly how he is doing, and can act as a reinforcer for the individual as he sees his behavior improve toward a criterion (a desired goal). Mark the criterion on the chart as the goal for which the individual is shooting, so that he can keep it in mind and view his progress. On Chart 1, the star at zero on the last day was the goal. Charting will also help to show if a program has not been successful, and generally will help the respite provider become a more astute observer of behavior.

12. One more procedure a respite provider is likely to find helpful in managing behavior is called "contracting." Contracting is a simple procedure in which the individual and respite provider make a deal with each other regarding their behavior. For example, a respite provider may want the person to clean up after himself whenever he has finished playing with his toys, but the individual usually refuses and leaves the mess. The individual, on the other hand, would like the respite provider to play a game with him, but the respite provider has other things to do and does not really want to play. In this situation, the respite provider and individual can "draw up" a contract and agree that whenever the person has picked up after himself when finished playing for the day, the respite provider will agree to play a game of the individual's choice. Then, if either the individual or the repite provider breaks his agreement, the other is free not to follow through on his part. These contracts should be written, signed (when possible) by both the respite provider and individual, and a copy made for each.

13. Contracting may be used in any number of situations for any number of behaviors the respite provider wishes to deal with. Again, of course, positive reinforcement should be given to strengthen these behaviors.

Remember, the goal should be for the individual to respond best to praise and positive attention. Contracting also has the advantage of making the individual feel a part of the process, and give him some control, which also helps him to deal with responsibilities.

E. Developing New Behavior

1. At times, just increasing desirable behaviors and decreasing undesirable behaviors is not enough when working with behavior problem individuals. The point has been made that providing alternative behaviors is important. However, if the person has never learned the behavior providing as an alternative, how will he be able to perform it correctly? Similarly, how will the person develop new desirable behaviors to use in novel situations in which the child has no idea of how to behave? Clearly, the individual will have to rely upon old and possibly inappropriate behaviors, unless there is a way he can learn new and appropriate ones.

2. "Modeling" is a most efficient way of teaching and developing new behaviors. Basically, modeling is learning that occurs through the observation of other people's behavior. Examples of how children learn by imitating adults or other children are easy to think of. Everyone, not only children, learn new behaviors by watching others and then imitating those behaviors. Thus, modeling can be a very effective tool when dealing with behavior problems.

3. Using modeling effectively involves several basic concepts. First, observing a model will increase the possibility of the individual behaving in a similar fashion. Whereas this does not mean that the individual will always imitate what he sees, having seen a certain behavior in a certain situation increases the chances that the individual will behave similarly in a similar situation. This is especially true if the situation is a novel one. A second concept involves the fact that the consequence the model receives for his behavior (was the behavior reinforced or punished?) will affect the observer. This means simply that if the model is reinforced for his behavior the observer will be more likely to imitate these behaviors, but if the model was punished the observer will be unlikely to imitate those punished behaviors. People tend to imitate those responses they know will bring positive reinforcers. Another concept involves what happens to the person after he imitates the model. Again, consequences are important. If the person imitates an appropriate behavior, it is important to positively reinforce this behavior to encourage this desirable response.

4. Respite providers should be aware of several other important facts about modeling. People tend to imitate a model's behavior more readily if they particularly like or admire the model. Although the most effective models may be members of the individual's own peer group, modeling is not restricted only to people who are similar to the observer. If it were, modeling would be a difficult process which developmentally disabled individuals. Effective models are people the individual wants to be like. Another important idea is that a person, for some reason, may not be able to perform a certain behavior, even though he has observed models. This tends to be particularly true with handicapped or developmentally disabled individuals. So care must be taken when using modeling to model behaviors

which the person is capable of performing. Conversely, just because a person has not performed a behavior that was modeled, it does not mean that the person has not learned this behavior. The situation must be right for the performance to be given.

5. How effective models can be is demonstrated consistently with Dennis. When with the respite provider and parent, who model appropriate behavior, Dennis engages in more appropriate imitation. Dennis also inhibits the more outrageous habits of spitting and cursing when with other models who do not indulge in or reinforce such behaviors. However, when certain peers who he likes engage in these behaviors and reinforce them, Dennis certainly does oblige them. Not all of the peers who reinforce such behavior are models for it too. Some of Dennis's peers are exemplary models but encourage Dennis with their attention by saying "You better not do it, Dennis!" Clearly, models can help encourage appropriate behavior, but they can also encourage inappropriate behavior, and care must be taken not to reinforce models who demonstrate inappropriate behaviors.

6. As with all other behavioral management techniques that have been presented, modeling will be most successful when combined with positive reinforcement. The respite provider can be a model for an individual by demonstrating desirable behaviors and behaviors which are most likely to be rewarded. The respite provider can and should model any positive behaviors which can replace undesirable ones. Finally, it is important for the respite provider to develop a strong relationship with the individual to become the most effective type of model.

7. The behavioral management techniques described in this chapter can be very effective in helping respite providers deal with behavior problems. The beauty of these techniques is that they are relatively easy to use. However, several points must be emphasized. To be effective, the respite provider must use these techniques systematically. This means the program must be planned carefully, and all the rules made clear to all. Finally, being consistent and always following through with the rules and consequences will help the program be successful. But perhaps the most important thing is to be creative with these techniques. Within the basic structure of positive reinforcement, punishments, contracting, and modeling, there are many ways these techniques can be used. The respite provider can use this variety to his/her advantage by being creative with these techniques. Do not be afraid to try things within this system, because the system can be easily changed if changes in the individual's behavior are not forthcoming.

8. While the respite provider will find these specific behavioral management techniques most useful, there are other important factors to consider when working with individuals with behavior problems. Always keep in mind that you are dealing with a person, and that person has needs, desires, and feelings as much as anyone else. Further, it must be especially frustrating to be developmentally disabled and different from most other individuals. The point is that the respite provider needs to be a sensitive person, with the ability to be understanding and sensitive to handicapped individuals. To be warm and caring as well as have good behavioral management skills is essential. Sometimes the best thing a respite provider can do is listen. Just listening to the person shows him

that you are interested in him and how he feels and that you care. Being sensitive warm, and able to listen will help develop a positive relationship. And as was noted earlier, such a positive relationship will make the behavioral program more successful as the individual will desire to please those people he likes and feels good about. Keep in mind that these personal characteristics can be as important as the systematic use of the behavioral management techniques, and frequently the parents of the children respite providers work with are looking especially for these characteristics.

9. One final point should be discussed. The respite provider is necessarily an extension of the parents in the home. As such, everything a respite provider wants to do must be done in conjunction with or with the cooperation of the parents. Do not be afraid to discuss your ideas on behavior management with the parents, but remember that their cooperation is essential. Similarly, the respite provider will have to learn the family's rules, and work within that system unless changes in those rules are mutually agreed upon. Also, the respite provider must take into account the family's own "pet peeves." One family may be terribly distressed over one behavior, while the same behavior may be of little consequence to another family. The initial contact and agreement between the parent and the respite provider should prevent any problems along these lines.

10. There are several additional short books concerning behavior management that a respite provider might find useful in learning these skills: Livin With Children, by G. Patterson (Research Press, 1968) and Families, also by G. Patterson (Research Press, 1971). Also, for a short discussion of behavior management in foster care homes, there is A Guide for Foster Parents, by I. Sarason, K. Lindner, and K. Ornic (Human Sciences Press, 1976).

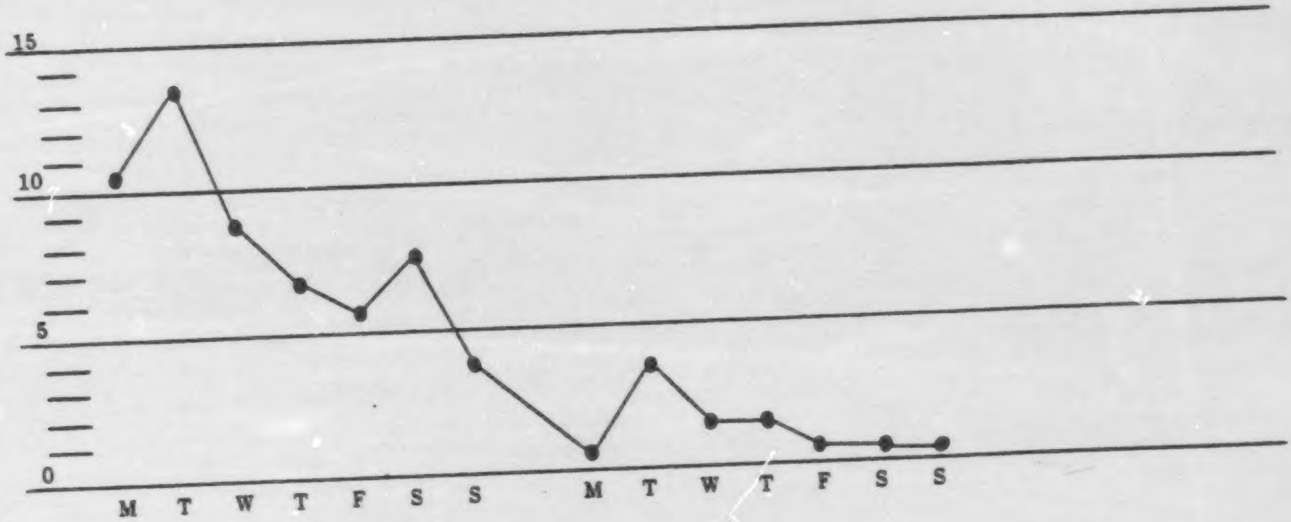
F. Case Study (to be discussed in class). Robert is an eight year old boy with several problem behaviors that were annoying to both his parents and the respite provider. Most annoying was his refusal to do what was requested of him. Whenever he was asked to do something, he would ignore the request and go about what he was interested in, say "No, I don't want to" and get into arguments, or say "O.K., but later" and then never do it. This almost always led to frustrations for the parents and the RCP. Arguments with Robert would end up with Robert having long, screaming tantrums.

Together, the parents and RCP developed a program to deal with Robert's poor behavior. They set the following program: a) Every time Robert was asked to do something and did not follow through, his bedtime was lowered 5 minutes. b) If Robert did follow through with three tasks in a row, he was given 10 extra minutes to stay-up time at night. c) If Robert were able to follow through with all that was asked of him for a week, his parents would take him to a park on the weekend as a special treat.

This program was not very effective. Robert's behavior did not change much, and he was losing one-half to an hour of bedtime each night. How might this progra be "debugged?" What needs to be checked?

CHART

Number of tantrums per day of
a child put on extinction



CHAPTER VI: FEEDING AND NUTRITION FOR THE HANDICAPPED

A. Introduction

1. In order for the growing child to develop properly, he must be adequately nourished. Because each family has its own pattern of selecting, preparing, and eating food, the respite care provider must familiarize himself with the family's food preferences when helping the child select the proper foods. It is important for the child to feel he is an integral part of his family in this important social aspect of his life—eating.

B. Nutritional Needs

1. Food is made up of nutrients that are necessary for life and health. Some nutrients are needed in large amounts, others in smaller amounts. The human body can survive and function with some deficiency in nutrients, but for full vitality these nutrients are needed in the right amounts at the right intervals. Malnutrition occurs when the diet is deficient, or when certain nutrients are consumed in quantities that will produce obesity or tooth decay. Malnutrition hinders developmental progress and reduces the vigor and initiative needed for maximum and physical and mental growth. The quality of nutrition can make a tremendous difference in the growth of the handicapped child, who already faces obstacles to his development.

C. Basic Meal Planning

1. For ease in meal planning, foods have been divided into four basic groups. The number of servings per day and the size of the servings from each group will vary with the age, size, body build, and individual nutrient needs of each person.

   a. The MILK GROUP is the basic source of calcium needed for strong bones and teeth.

   b. The MEAT GROUP (which includes fish, poultry, eggs, cheese, nuts, and dried peas and beans in addition to meat) is the basic source of protein.

   c. The VEGETABLES AND FRUITS GROUP provides minerals, vitamins, and roughage.

   d. The BREADS AND CEREALS GROUP is the basic source of carbohydrates and the B vitamins.

D. Special Diets

1. Many chronic diseases require modification of the diet in order for the body to safely assimilate essential nutrients. There are basically three types of management plans for special diets: the MEASURED DIET, the EXCHANGE DIET, and the RESTRICTED DIET. In some cases these types of diets may be combined or alternated.

   a. The person on a "measured diet" may have a diet prescription that specifies exact amounts of certain nutrients he must have at specified time intervals. In this case, the parent will have a list of foods indicating how much of the nutrient each food contains. The person's food for the day is planned according to how much of the nutrient is permitted or required. Everything the person eats must be measured or weighed accurately and then recorded on a form provided by a nutritionist.

b. If "exchange lists" are used in meal planning, the parent will have lists of permitted foods, with a prescribed amount of each food designated as an exchange. A diet prescription will specify how many exchanges from each list are permitted each day. Any food on an exchange list may be substituted for any other food on the same list, as long as it is used in the quantity specified.

c. The "restricted diet" is used in cases in which there are certain foods or nutrients a person may not have or may have only in limited quantities. When handling a restricted diet, it is important to become a habitual label reader. For example, corn syrup is used in many prepared foods and can be a hidden source of trouble for the person allergic to corn. In addition, some foods may be hiding under less common names, such as glucose or lactose, which are forms of sugar.

2. If the person you care for is on a special diet, be sure you understand thoroughly all the procedures that must be followed. Ask the parent to explain and demonstrate, and ask questions about any point that is not clear to you. It is vital to the child's health, and sometimes his very life, that his diet be followed accurately.

3. In some cases, as in diabetes, the intervals at which food is eaten is important. In this case the child must receive a certain portion of his food at certain times of the day. Learn what the intervals are and how to recognize if the child shows symptoms of needing food.

4. In homes where it is important to keep certain foods from the child, follow the parent's instruction for keeping food locked, out of reach, or in certain locations; for clearing away food after meals; for disposal of garbage; and for storing and using pet foods.

E. Diet Acceptance

1. We have now learned what basic foods humans need for good health, and what restrictions may be necessary for children with certain problems. However, the nutritional value of the food is not the only consideration in meal planning. The food must also be appealing to the child, for he must eat it in order to benefit.

2. A primary consideration is to keep the diet within the family's individual pattern of eating (as much as possible), because familiar foods will taste best to the child.

F. Eating Skills

1. Once a nutritious meal has been provided, and the person is eager to accept

it, the person must have the physical skill required to bring the food to his mouth, and chew and swallow it. This seems like a simple task to the adult, but it is actually complex and difficult for the very young child or the child whose handicap has prevented him from developing these skills.

2. Preparation for self-feeding begins during infancy when a baby puts his fingers and toys into his mouth. Use of the tongue and lips progresses with maturity from exploring fingers and objects to the ability to handle food. When strained foods or baby cereal are first offered to the infant (4-5 months) he may seem to reject it. Much of the food is pushed back out of the mouth as soon as it is put in. This is because the child is using a tongue and lip pattern which worked successfully on a nipple, but which must be modified to a more mature level. It is important that a child have the opportunity to take food from a spoon at this age so that he learns how to use his mouth without using the sucking pattern. At first, the food offered will be strained or soft. When he is able to eat that kind of food without difficulty, lumpy foods and beginning finger foods can be introduced. Each child should follow the normal sequence of eating skills, although a handicapped child might proceed at a slower rate. Notice the eating skills associated with each level of physical motor development.

G. Normal Development of Skills Related to Eating

Birth: Lack of head and trunk control requires total support. Head in line with body or slightly forward, not tilted back. Sucking is with jaw movement. Consumes liquid from a nipple.

1-2 mo: Beginning head control, still requires support while eating. Some hand to mouth movement. In and out tongue movement causes involuntary loss of food. Continues on liquids and may start cereals and strained fruits.

4-5 mo: Head control, uppertrunk control. May sit in infant seat or propped in high chair. Frequent hands to mouth. Reaches with 2 hands, maintains grasp on objects bringing them to mouth to chew and suck. Draws bottle to mouth with assistance but releases hands when nipple inserted. Negative pressure suck. Eats strained foods. Cereals stay in mouth better.

5-6 mo: Sits in high chair with some support. Continues exploration of toys with mouth, total hand used for grasping. Munching begins. More variety of tongue movement. Consumes mashed and soft foods.

6-8 mo: Sits well in high chair, holds bottle alone, transfers objects between hands, reaches for dish, spoon; brings mouth forward to spoon. Bites and chews on toys; chews easily dissolved foods; finger feeds crackers; total hand grasp requires large pieces.

Soda crackers, teething biscuits, cheese stick, bread sticks, vienna sausage. Eats chopped foods (some chewing expected).

8-9 mo: Sits indefinitely unsupported, hands free for object manipulation. Finger feeds bite-sized foods. Can grasp small pieces.

Lips more active when chewing, close when swallowing.

Consumes bite-size food.

9-11 mo: Uses cup, spoon in play, exploring their use, imitating adults.

Bites off correct amount.

Eats table foods that are easily chewable.

12-18 mo: Finger feeds self much of meal--messy.

18-24 mo: Holds cup to drink; one or two hands depending on size of cup - (usually starts with two)-often spills, drops cup.

Begins spoon feeding. Sticky foods are best (mashed potato, porridge, pudding).

Increased coordination and strength in handling solids.

Eats chopped ground meats and fresh vegetables.

1. The following suggestions might be used to promote learning at different stages of development.

   --If the child is not able to physically participate in feeding, then encourage visual attention by feeding him only when he is looking at the food. He may tend to look at your face, and this is desirable except when food is being brought to his mouth. Put the food between your face and the child when he is ready for the next bite and wait for his attention to it.

   --If the child never brings his hands to his mouth, hold his wrist and slowly guide his hand to his mouth.

   --If a baby bottle is used, encourage or assist him to place his hands on the bottle; gradually withdraw assistance.

   --If the child does not bring objects to his mouth, assist him by placing something in one of his hands (of a size that is easy to grasp such as a soft rubber toy) and help him move it to his mouth (hold his wrist or put your hand directly over his).

   --The next step is to assist the child to bring finger foods to his mouth. Larger objects are easier to grasp. As hand skill develops, the child will be able to pick up smaller pieces. This can be checked by making a variety of sizes available and observing how he does, thus ensuring success with at least some of the foods.

   --Spoon feeding can be initiated with the child's hand on the spoon and the adult's hand on top. Provide less assistance as the child is able to take over. Learning to use a spoon is much easier when the food sticks to the spoon (mashed potatoes, pudding, yogurt, and hot cereal).

   --If the child takes liquids from a cup, assist him only as much as necessary in holding the cup while drinking and putting it down safely; you may want to dry different sizes of cups to see which works best. Praise the child's efforts and partial successes.

2. If a child resists your assistance, try to analyze whether the cause is involuntary (muscle tightness, sensitivity to being touched) or voluntary (difficulty accepting change of food, fear, dislike of the offered food, or the desire to be independent). Involuntary resistance requires special methods—ask the parents about the procedures they use to overcome the resistance. Voluntary resistance can be handled with changes of environment, food or approach.

3. When possible, observe the child eating a meal or snack in his usual mealtime location. Look adaptations on the chair and observe the child's position in the chair. Is he sitting up straight? How fast does he eat and how much assistance is provided? Ask questions to clarify observations (e.g., "Is that how he tells you he's not hungary?").

H. Eating Problems

1. When should you encourage parents to seek a feeding evaluation if one has not been done recently? If any of the following behaviors are exhibited consistently, you should indicate your concern to the parents.

   a. Intolerance of lumpy foods and solid foods beyond the age of 18 months.

   b. Frequent coughing or choking when eating.

   c. Inability to keep most food and liquid inside the mouth and swallow i beyond the age of 5 months.

   d. A tendency to bite down hard on the spoon.

   e. The inability or lack of motivation to bring the hand to the mouth beyond the ages of 3 months.

   f. Abnormal sitting posture.

   g. Persistent tongue thrust beyond 6 months of age.

2. Seek out assistance through the child's physician or the local health department.

I. Body Positioning

1. Body position during eating is extremely important. If the child feels insecure, he will not be able to focus his efforts on chewing and swallowing. The ideal position for eating is upright sitting; however, if a child has poor head control or difficulty keeping food in his mouth, a chair with a backward tilt (15-45 degrees) from vertical with support for the head will be helpful. Laying back more than 45 degrees may cause food or liquids to fall into the lungs. For children who are small enough to be held and who cannot be positioned and controlled adequately in a high chair or infant seat, there are several possible ways to hold the child. Some adults prefer to sit on a couch with an armrest, particularly if they are supporting the child with one arm (usually left) or providing jaw control for the child. When a child sits sideways on an adult lap, his hips should

be between the adult's knees, so he will not slide off. One foot can be placed on a stool or on the opposite knee to form a backrest for the child. For good eye contacts place the child's legs around your body as he sits on your lap facing you, with a pillow supporting behind him, and put your feet on a stool. See pictures at end of Chapter.

J. Infant or Small Child Feeding Positions

1. The head position in relationship to the body is extremely important. When the head is tilted back (this often occurs when there is a problem with muscle tightness or weakness), gravity pulls the liquid or foods to the back of the mouth. The opening to the lungs is open when the head is tilted back. Eating or drinking with the head in that position increases the chances of choking. Head support can be provided with cushions, chair adaptations, or by holding the top of the head with one hand. Remember to look at the rest of the body. If the arms are pulled back at the shoulders, the head tends to be back; getting the arms forward will improve the head control and prepare the child for eventual hand use. Does the child wince or withdraw when touched near or inside his mouth? If so, before offering foods, help the child get use to having his gums rubbed gently but firmly either with your finger or with his (guided by your assistance) only outside the teeth so you do not get bitten. Tooth brushing with a soft bristle toothbrush after meals will normalize sensation and help keep gums and teeth healthy.

2. When offering the child food from a bottle or spoon, approach the child's mouth from a low angle, when he is looking at it. Avoid moving too quickly towards his face. Encourage him to bring his head slightly forward to make contact. For a child who tends to turn his head to one side, offer food only directly in front of him.

3. Swallowing will occur when the mouth is closed, following up and down jaw movement. Wait for a swallow response if it does not occur immediately after chewing movement. Primitive tongue movements (forward and back) may persist long beyond the developmental level of 6 months when they should be starting to show more variety. Stimulating the side of the tongue and providing food or toys for the purpose of chewing will result in greater variety of movement, e.g., provide objects that can be held securely outside the mouth at the side.

4. If the child starts coughing or gagging on food, observe him carefully to see if he is able to get his air passage cleared. When the child has difficulty, get his head down before patting sharply between the shoulder blades or before reaching in and trying to dislodge the obstruction. Do not hit his back while he is upright. The food piece may become more firmly lodged.

5. Some children may bite down hard on the spoon involuntarily (this is known as "bite reflex") and may not be able to release it. If this should happen, press down on the tongue with the spoon, then release pressure and wait till the mouth opens. Be careful of your fingers and those of the child whenever fingers are put into his mouth.

K. Adaptations

1. Adaptive equipment may be recommended for the child. Learn the proper use of such equipment from the child's parents. Department stores can often meet special needs. For instance, there are many kinds of baby bottle nipples on the market. Some of which will work better than others depending on the child.

2. If a child has difficulty with drinking from his bottle, another kind of nipple may be the answer. Be cautious about greatly enlarging the hole of the nipple. Some nipples are softer and flow easier, such as the "premie" nipple. Devices which feed the child strained food through a nipple are generally undesirable because the child does not get to practice the more mature pattern of taking food from a spoon.

3. "Tippy cups" usually have two kinds of plastic lids. Avoid the one with the spout. It tends to reinforce less mature oral patterns. The depressed lid with two small holes helps the child regulate liquid flow and also cuts down on spills when the cup is dropped. The kind with two handles might be preferable for a beginner.

4. Hand-cranked food grinders can be very useful to prepare meals for children who lack chewing skills. Soft rubber toys intended for infants are good for learning to chew.

5. The size of the spoon bowl should not be greater than the inside dimension of the child's mouth. If the child bites the spoon, a teflon coated spoon will be less abrasive. When a child is first learning to use utensils, there is often difficulty in learning the wrist and hand movement to get the spoon to the mouth without losing the contents of the spoon in the process. There are now soft rubber utensils for young children which feature curved handles. Most are designed for right handed children, but can be heated and bent for left handed children. Metal spoons can also be bent near the base of the handle. Bowls and plates with rims are helpful when trying to push food onto a utensil.

6. The Bobby Mac Infant Seat, a J.C. Penney product, has been highly recommended by several parents. It can be used as a car seat, high chair, stroller, and infant seat. The sitting angle works well for a child with no head and trunk control. Bean bag chairs work well for some children but may not offer enough support for others.

7. Adaptations should be made only when necessary. Examples of some adaptations which can be made at home are as follows:

    a. If head support is needed and the chair back is not high enough, insert a piece of wood that extends from the inside of the chair back to the desired height. Rolled up towels can be used in various ways: on either side of the trunk for support (assuming the chair has arms which keep them in place), or behind the head to improve head position.

    b. If a child involuntarily slides out of his chair, several options can be considered depending on the severity of the problem:

        (1) Be sure his feet are supported and the chair depth is

appropriate.

(2) Place a seat belt at the hip level, not at the waist.

(3) Try a non-skid mat on the chair seat.

(4) Put a wedge cushion or rolled towel under the knees.

(5) Try leg ties at the hips. The leg ties can be made from nylon stockings or pantyhose or from 1 inch wide webbing straps. Fasten these at the back of chair seat and leave them long so they can be fastened around the back of the chair.

8. A damp wash cloth under the plate will stop it from sliding around on the table. A wash cloth can be wrapped around the handle of a spoon and secured with elastic bands in order to build up the size for a person with weak grasp or limited flexibility.

9. Flattening the bowl of a spoon with a hammer is helpful for persons with limited use of the upper lip, e.g., those who have difficulty getting the food off the spoon. Tongue blades can also be used for the same purpose. The end of a metal spoon can be bent in a vise to resemble commercial models for limited wrist movement.

L. Analysis of Food

1. When new foods are introduced to the child, carefully observe the child's ability to handle it appropriately in his mouth. It is often helpful for the adult to eat various foods slowly and analyze the level of difficulty before offering it to the child for the first time.

2. Liquids are easier to handle when cold or warmed and when thickened. Examples: buttermilk, eggnog, yogurt thinned, apricot nectar, milkshakes. Tapioca, cornstarch, or unflavored gelatin can be used as a thickener.

3. Beginning finger foods should dissolve in the mouth after two or three chews. A crunchy quality gives good sensory stimulation. Examples of beginning solids include: baby toast, plain vanilla cookies, soda crackers, dry cereal, toast strips, cheese sticks, vienna sausage. More advanced finger foods include sandwiches and raisins. The most difficult foods are coarse foods that do not dissolve and that require extensive chewing, e.g., popcorn, nuts, raw vegetables, and meat.

4. Multi-textures that involve handling a solid and a liquid can be difficult for a child with incoordinated oral structures. Multi-textured foods include watermelon, vegetable soup, grapes (skin needs to be chewed while liquid is either retained or swallowed).

5. Taste and temperature stimulate chewing and swallowing. Children often like spaghetti, possibly because it is flavorful and colorful. Check the temperature on your wrist. Cold, tart yogurt is also popular. Food likes and dislikes of children should be respected. Forcing children to eat foods they do not like or trying to get them to eat when they are not hungary can lead to difficult behavior problems and distorted attitudes

toward food.

M. Snack Ideas for Growing Children

1. Because preschool age children have increased energy needs due to growth and activity, it is best to offer a planned between meal snack of wholesome foods at regular times each day - No Nibbling! The following suggestions for snacks may be helpful in selecting a variety of foods.

BEVERAGES
Fruit Juices, especially citrus
Tomatoe or Blended Vegetable Juice
Milk, Ice cream floats
Fruit punch, fresh lemonade or orangeade

HIGH IN IRON
Hard boiled egg slices or stuffed egg
Luncheon meat, cubes or slices
Hot Dog wedge
Meat spreads - Liver, chicken, ham, etc.
Baggie of Dry Cereal

PROTEIN FOODS
Cheese cubes or spreads with cracker or bread
Peanut butter with cracker or bread
Dips - Bean, cheese, meat with chips, cracker or vegetable or vegetable slices

OTHER
Puddings
Ice cream cones
Nuts

FRUITS Use a variety of flavor and form - serve in wedges, thin slices or strips, unpeeled.
Fresh fruits in season
Dates, prunes (pitted), raisins
Melons

BREAD AND CEREAL FOODS
Crackers - Saltines, Graham, Ritz, Wheat
Bread - Whole grain or enriched white
Fruit Bread - banana, pumpkin, raisin
Cookies - oatmeal, peanut butter
Cinnamon Toast
Tortilla with butter

VEGETABLES
Raw vegetables - sticks, wedges, slices or strips
As carrots, celery, cabbage, green pepper, turnips, tomatoes
Use celery filled with peanut butter or cheese filling

2. Foods which should not be used as snacks - candy, pop, Koolaid, Jello Water.

3. If child chokes easily, as an infant or handicapped child, use judgement - No nuts, raisins, popcorn, dry cereal.

4. Teach child to drink water after eating to clean teeth.

5. Strips of fresh fruits and vegetables serve as "Nature's toothbrush" and help develop tongue movement for speech.

CHAPTER VII: COMMUNICATING WITH THE HANDICAPPED

A. Introduction

1. The handicapped, with language and communication problems, pose a serious problem for everyone who is responsible for their care and well-being. Those individuals who have little or no verbal language or speech present a particularly urgent concern. We shall refer to those individuals as "non-verbal." A failure to develop verbal speech may be the result of a variety of handicapping conditions. An individual may fail to develop speech as the result of deafness, severe physical or intellectual handicaps or a combination of disabilities. These individuals are unable to tell people their needs or feelings or share their thoughts and problems with others.

2. This chapter will discuss the problems of the non-verbal person and their families. It will suggest ways, other than speech, that the person may communicate. Sign language, communication boards, and hearing aids will be major topics, as well as a method for encouraging communication.

B. The Importance of Communication

1. Communication is important to all of us. Communication does not occur with just one person. Communication occurs only when two or more people exchange ideas. If one is not able to communicate, he is isolated from other people and unable to control what is done to him. It is through communication that we let others know what we want and in this way exercise control over our own environment. The most common means of communication is through speech; however, should this method be nonfunctional, then an alternate means must be sought. The purpose of an alternate communication method is to give a person a way of "talking" with people, other than through speech. For many years sign language has been an efficient means for the deaf to communicate. Recently, sign language has been introduced to other non-verbal, yet hearing people with encouraging success. Communication boards, books or cards offer another language alternative. These devices allow the person to "talk" by pointing to words, letters, symbols, or pictures. Thus, there are options for the handicapped individual who is deprived of speech. These alternatives will allow the person to share feelings, communicate desires, and become a participating member of the family.

2. In addition to the obvious handicapping condition of the non-verbal individual these children may seem disruptive or they may exhibit unusual behaviors that do not seem related to communication. Non-verbal individuals do not always express their emotions as do verbal individuals. Sometimes a child will not cry when he is in paid, he might bite himself or become overly active. Do not assume--ask the parents how their child usually expresses his feelings. It is difficult for those of us with normal language to appreciate what it would be like not to be able to understand what people are talking about or to let others know what we are thinking about or wanting or feeling. By turning the volume of the T.V. off, we get an idea of what it must be like to watch people's lips move and have no idea what they are saying. This experience was given to one youngster in hopes of helping him understand the frustrations of his deaf

sister. The results were unexpected: he kicked, banged, and slapped the T.V. set because he was unable to understand what his Sesame Street pals were talking about. The child's frustration was easily remedied by telling his mother his problem. This episode points out a normal child's reaction to an inability to participate in just one portion of the communication process—understanding speech. It is not too surprising that individuals totally deprived of communication may act out in ways that seem odd and, in some cases, quite bizarre. Parents of non-verbal children have observed kicking, biting, head banging, unexplained crying spells, destruction, various self stimulating behaviors, and an eventual withdrawal into the child's own private world.

C. Alternative Communication Methods

1. The primary communication alternatives are sign language and communication boards. The following definitions will be helpful in understanding the rest of this chapter.

   a. American Sign Language (Amslan) is a language system in and of itself. The ordering of words (syntax) varies from English, and some words are not signed, e.g., word endings and articles. Amslan is commonly the communication system of deaf adults and interpreters for the deaf.

   b. Total Communication (Signed English, Manual English) is the simultaneous use of spoken and signed English. This method of communication has a one-to-one correspondence between signs and spoken English. It is presently the popular instructional method in schools serving severely hearing impaired children.

   c. Fingerspelling is the spelling of a word, letter by letter, using the manual alphabet. It is possible to represent a word in manual communication in two ways: through sign or through fingerspelling. For the accomplished user of any form of sign language, a combination of both signs and fingerspelling is usually used in communication.

   d. Language boards, books, or cards offer a graphic (words, and/or symbols, and/or pictures) display which allows the person to point to, or otherwise indicate items in order to communicate with another person. They are often "homemade" and may either be quite simple or quite complex. Perhaps the most useful are those which are portable because they can be carried with the individual and are constructed specifically to meet the needs of the individual.

D. Sign Language

1. Within recent years, sign language has gained recognition and support throughout our communities. It has been found that a child's use of sign language does not interfere with his potential to develop speech; in fact, it assists in the development of a language system. Presently, a Total Communication (signs and speech in combination) program is available in nearly all school programs for severely hearing impaired children.

2. Greater public awareness of sign language has contributed to the interest in its potential usefulness for hearing, non-verbal individuals. Programs

which have introduced sign language as a speech alternative have had encouraging results. In considering sign language and how it is taught, some reasons can be suggested as to why it has been so successful with some non-communciating, hearing individuals. Sign language is symbolic, that is, many of the signs make sense and they look like what they mean. For example, the sign for baby is a gentle rocking motion of folded arms; "eat" is a motion of the hand to the mouth. Another reason which contributes to its ease of instruction is that a sign can remain static. That is, a sign can be held so that the person can imitate it and make his hands do the same, or an adult can help the child with the hand formation. This is a big advantage over speech as it is quite impossible to crawl inside the mouth to tell the tongue where to put itself. Furthermore, the individual has an easier chance to have quick success in communication, and, of course, the more success--the more likely he will be to try it again.

3. Sign language does have limitations which must be considered. One of the most obvious is that the person has a limited audience to communicate with. Only people who are familiar with the signs the individual knows will be able to understand him. Another consideration is the physical ability of the individual. The person may lack the physical hand and arm coordination necessary to form signs clearly enough to be understood. The Speech Pathologist (Communication Disorders Specialist) and other professionals will provide valuable input regarding the appropriateness of this alternative communication method.

4. Fifteen signs are pictured at the end of this chapter with a brief description of how these signs are formed. They represent only a few essential activities of daily living. An individual who will need any substantial vocabulary of signs should read those resources listed at the end of the chapter. Always remember to check with parents and other people in the living situation to make sure the signs you are using are those the child is familiar with.

5. Guidelines for using sign language:

   a. Sign should be made directly in front of the body at chest level unless otherwise indicated.

   b. Sign slowly in an even manner. Signs which are made too quickly, too slowly, too sloppily, or at an uneven rate are difficult to understand.

   c. Maintain eye contact. Always face the person with whom you are communicating.

   d. Use normal volume of voice when speaking and signing at the same time. In this way the person receives the greatest information.

   e. Be clear and precise in both signing and speaking. For some individuals it may be necessary to overemphasize the sign by making it larger, repeating it, or making it slowly.

   f. One does not need to be an interpreter for the deaf, i.e., as fast as a speeding bullet, to be effective communicating in sign language. A person may not remember a lengthy string of words. The most effective messages will be signed clearly and concisely and allow the person some way of showing he understands.

g. Use expression in face and body when signing. The exact procedure is not as important as the attempt. When the individual does not understand the sign, use pantomimes.

E. Communication Boards, Books, or Cards

1. These communication devices are another alternative for communication. This system has advantages over sign language in that more people are able to understand the person and these communication devices need less precise physical (hand-arm) control. However, it takes longer for the individual to express himself, and this requires a patient "listener." Using such a device, the person points to or otherwise indicates pictures, and/or symbols, and/or words, and/or the alphabet. These items may be placed upon an electronically controlled reader board, though more commonly they are "custom made" at home or school. One option is a large sheet with the items placed on it which is fitted into a wooden frame attached to a wheel chair. A looseleaf notebook may also be used with pages containing words or pictures to convey messages. Another method is a set of pictures and/or word cards attached with a key ring. These are several ideas available, and the selection of a device best suited for a person will come after serious consideration and consultation with those who know and work with the individual.

2. Guidelines for using language boards, books, or cards:

   a. The visual communication device must be readily accessible to the individual at all times.

   b. One must be patient with the person to allow him enough time to make his selections. For those individuals with severe coordination problems it will be laborious, though rewarding, to point out the message.

   c. The system must be flexible enough to expand with the growing ability and needs of the individual. This is a reason why a homemade device may be particularly helpful as it is usually quite easy to add new words and can be expanded to meet the needs of the individual.

   d. The person needs to be aware of the communication characteristics of the person in order to know how the individual makes his message understood. Some individuals using language and alphabet boards prefer to spell or to point out their entire message. Some would rather have a person guess words they are trying to "say." For example, one person may spell out the entire word "hamburger" although it may take some time, whereas another individual would prefer that the word be guessed at after a few letters are indicated.

F. Care and Maintenance of Hearing Aids

1. Maximum usage of the hearing an individual possesses is a primary

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consideration for hearing-impaired people. For individuals who function with a hearing aid, this can only be accomplished through effective use of their hearing aid. It is of utmost importance that the respite care provider be familiar with the parents' method of placing and removing the aid from the person, the individual's attitude towards the aid, the hours of the day he wears the aid, as well as the care and maintenance of the hearing aid.

2. A hearing aid is a battery operated miniature amplifying system which consists of a microphone, conductive cord, and receiver. Although it appears small, it represents a significant financial investment. The three types of aids are: the one concealed in the ear piece of glasses, the one placed behind the ear, and the third, and usually most powerful, body style contained in a small case (2" x 3") and attached to the individual.

3. The "life" of a hearing aid may be directly correlated with its treatment. One unfortunate yet somewhat common demise results from water. Water and hearing aids do not mix. The aid should be kept away from baths, showers, raindrops, and lakes. Keep in mind that it may not occur to an individual not to wear his aid into the shower or pool. It has also been reported that an effective escape route for those hearing aids who do not like their wearers or vice versa is down the toilet. One flush and they are gone forever. Another danger can be dogs or other guests irritated by a strange high pitched whistling. This can be very distressing particularly to dogs and the person is likely not to be aware of it. High pitched whistling is the result of "feedback" occurring when the receiver is too close to the microphone (ear molded to the body of aid). This may occur when the aid is turned up to high level or when the ear mold does not fit snugly in the ear. Some basic considerations for the care and maintenance of the hearing aid are:

   a. Use fresh batteries. Throw away exhausted batteries. Do not re-use them. Batteries may last 5 to 14 days depending upon the user.

   b. Batteries should be removed from the aid when not in use and stored in a cool, dry place.

   c. Never let batteries contact coins, keys, or each other. Several seconds of such contact will exhaust batteries completely. Keep the aid in its container.

   d. Always buy the batteries recommended for the aid by the dealer.

   e. Do not turn up the volume control more than necessary to get clear, distinct sounds. Be familiar with the child's usual setting level and check the aid periodically to make certain it is turned on. Listen to it to confirm sound clarity. The best selection should be received at the middle of the switch selector.

   f. The hearing aid should not be worn if there is evidence of drainage from the ear. This may indicate an ear infection. The parent should be notified so that the physician can be consulted.

   g. The hearing aid is a delicate piece of precision engineering and should not be dropped, tampered with, or swung by the end of a receiver cord. Do not open the transmitter case to "see what makes it tick."

G. Helpful Hints

1. Regardless of the communication methods used, these are considerations which will make the exchange easier for everyone:

    a. Many people with communication problems will have a difficult time understanding what people are saying to them. It is important that what the adult says refers to the here and now—the immediate situation. The message should be worded simply and directly using vocabulary which the person is likely to understand.

    b. Meaningful facial expressions and body posture, when combined with the message, help the individual understand what is being said. For example, when using the word "good," a smile and a feeling of approval will help convey the meaning.

    c. The individual's communication should be as accurate as he is capable of, but it is important to acknowledge and to respond to his attempts. The goal is to encourage communication although it may be crude in the early stages. As the individual becomes better at using communication methods, he will become easier to understand.

    d. Encourage the individual to communicate. If every desire is met before the individual has an opportunity to "tell" his wants, the child will not get practice using communication. He/she will be unfamiliar with the use of communication as a tool to control his/her environment and may therefore need to be encouraged to use it. By using communication in the natural "real life" setting the person is given opportunities to practice the skill meaningfully and effectively and, as in any other task, the more practice using it, the easier it becomes.

H. Encouraging Communication

Everyone who works, plays and cares for an individual is, in a sense, his teacher. Learning is not confined to classrooms but occurs throughout the day. Both the normal and handicapped individuals learn language by communicating with others about things they are doing together. For these reasons "talk" (through whatever means) while doing daily activities, working, and playing. For example, when cleaning up ask, "Which things go in this cupboard?" "Where do the spoons go?" etc. There are many opportunities to communicate with a person and the caretaker needs only be aware of these opportunities and how to make the most of them. The following suggestions will provide some examples of how an adult can help the child learn and use language in a meaningful way.

I. Talk to the Individual

1. Talk about what you are doing when you are doing it. Help the person become aware of his surroundings and realize that each object has a name. In this way the individual will associate words with objects and actions

which they represent and the person will learn new words for new things encountered. Give the individual an opportunity to see the connection between words and the things they refer to. Do not just give him a glass of juice. As you do, always say and/or sign "juice." While getting a meal ready, share what is being done with the person. Someone might say, "We need water in this pan, yes, a little more. Let's put the water on the stove now so it will get hot. The water is hot now so we can put in the corn." Making cookies, going shopping, and visiting people are the types of experiences which provide a rich opportunity to learn and use words. A walk to the store may provide practice for using words such as stoplight, people, bus, police, etc. A trip to the zoo may offer a time to introduce new words such as elephant, lion, grass, tree, squirrel, etc. With each experience, the individual's vocabulary grows so he has an increasing number of things to "talk" about.

2. It is particularly important to keep talking with the non-verbal individual. Typically, language input may be neglected because they do not talk back or respond to comments. One will need to remind oneself to keep talking as if expecting the person to comment. In conversations, turn to the child politely and ask what he thinks about the matter. In this way, even without knowing what is going on, the individual will feel a part of it.

3. It is equally important to remember to speak about things you want the person to hear. Keep private conversations out of the child's presence. Though he or she may not "speak up," the individual will understand a non-verbal cue and he or she has sensitive feelings the same as others.

J. Listen to the individual

1. Help the person become an active member of the home environment by including him or her in conversations and acknowledging communication attempts. Listening/watching the individual's comminication will mean taking extra time and effort but it can do a great deal toward helping the person realize that he is an important person and other people are interested in his contributions. At times it may be difficult not to jump in and second guess the individual's intended meaning, but the strongest recommendation is to hold back, be patient, and let the individual show how much he is capable of. Because the individual may have a limited vocabulary, he may have difficulty remembering or even knowing which word to use. When it is apparent the person is struggling, the adult may subtly supply the word.

2. Provide the individual with every opportunity to communicate. Ask the person what he wants or expects and encourage him to respond, "I want ____." Invitations to communicate should be offered such as saying goodbye, hello, and thank you. Providing the individual with the opportunity to make choices, "Do you want the red shirt or the blue shirt?" is an excellent way of encouraging his participation, as well as showing the individual that communication will give him control over what happens to him.

3. In order for the individual to communicate, he must have something to communciate about. By including him in family discussions he will become

aware of the kinds of things people talk about. Encourage people to "talk" with each other as well as with adults about the things they did that day, who they saw, what happened outside, etc. The exchange of information will help him feel he is a part of his surroundings. Showing interest, listening patiently, asking questions, and adding additional information will indicate to the individual that his contributions are significant and appreciated.

4. The individual needs motivation to continue his communication attempts. The listener can help a great deal by displaying genuine pleasure with the individual's performance and then responding appropriately. For some individuals it will be particularly effective for the adult to exaggerate a little, "ham it up," as they say. This is also a good way to suggest the meaning of words being spoken.

K. Expand the Individual's Communication

1. Although the person's expressions may be short (one or two words) show him he was understood by repeating the sentence the way an adult would have said it. For example, if the person indicates, "drink," say, "Yes, you want a drink of water, I will put it in a glass for you." Individuals can also be encouraged to attempt longer phrases. This provides a model of the proper language construction.

2. If the child says, "drink," say, "O.K., tell me, 'I want a drink,'" and the person imitates (with assistance if necessary). Another suggestion is to set an example of a sentence pattern such as, "I have a red car, what do you have? A truck? What color is your truck?" It is this type of word play which teaches the individual sentence patterns and gives him opportunity to practice them.

L. Read to the Handicapped Individual

1. The individual may not read, but often will enjoy having someone read to him. While the reader may get bored with the same book again and again, chances are he will not. Some handicapped individuals enjoy repetition and appreciate showing that they know what comes next by turning the pages or pointing to familiar characters or common words. Local libraries have a fine selection of picture books and simple stories which people of all ages will enjoy.

2. When reading, it is advisable to speak/sign slowly and stop occasionally to point out action in the pictures or ask simple questions to see if he understands the story. Some individuals may be encouraged to produce language by asking, "What do you think will happen next?" or "Where is father going?" or "What is her name?" The meanings of vocabulary words should be explained simply, then confirm the comprehension by later asking, "What does that word mean?"

3. Reading need not be restricted to books. Identify package labels and cans of food. Point out the names of stores, street signs, and the individual's name by reading these words for them. Common experiences provide the best learning situations.

M. Play

1. Experiences with language can be provided through activities which are fun for everyone. Playing games together gives the opportunity to practice using communication in relaxed and happy situations. Simple card games such as "Go Fish" or "Concentration" are available commercially or may be easily constructed at home and require only a few vocabulary words. In these games the individual may develop the sentence patterns of common expressions such as, "I want blue," or "Do you have a cow?" etc. Other activities also may be arranged to provide language experiences. Keep in mind that beginning concepts are colors (red, blue), shapes (circle, square), and sizes (big, little). The individual may build a big block tower or a little block tower. The person may be asked to see if the big car will go under a little bridge, or if a big doll will fit into a little house. These are moments the individual may discover for himself the meaning and power of using language.

2. The following are offered as suggested activities which will be fun and help develop language naturally:

   a. Pantomiming familiar actions.

   b. Playing homemade musical instruments.

   c. Imitating animal movements.

   d. Following an obstacle course.

   e. Tea party pantomime.

   f. Acting out familiar experiences.

   g. Acting out going places.

   h. Recognizing familiar eating utensils.

   i. Matching identical objects.

   j. Matching pictures and objects.

   k. Recognizing household objects in pictures.

   l. Sorting the family clothes.

   m. Matching circles, squares, triangles.

   n. Naming what is red and what is not red.

   o. Making a chain of alternating colors.

   p. Pairing objects that go together.

   q. Imitating a series of actions.

r. Remembering where things belong.

s. Imitating actions in pictures.

t. Copying an arrangement of three objects.

u. Matching objects to their outlines.

v. Sorting clothes by season.

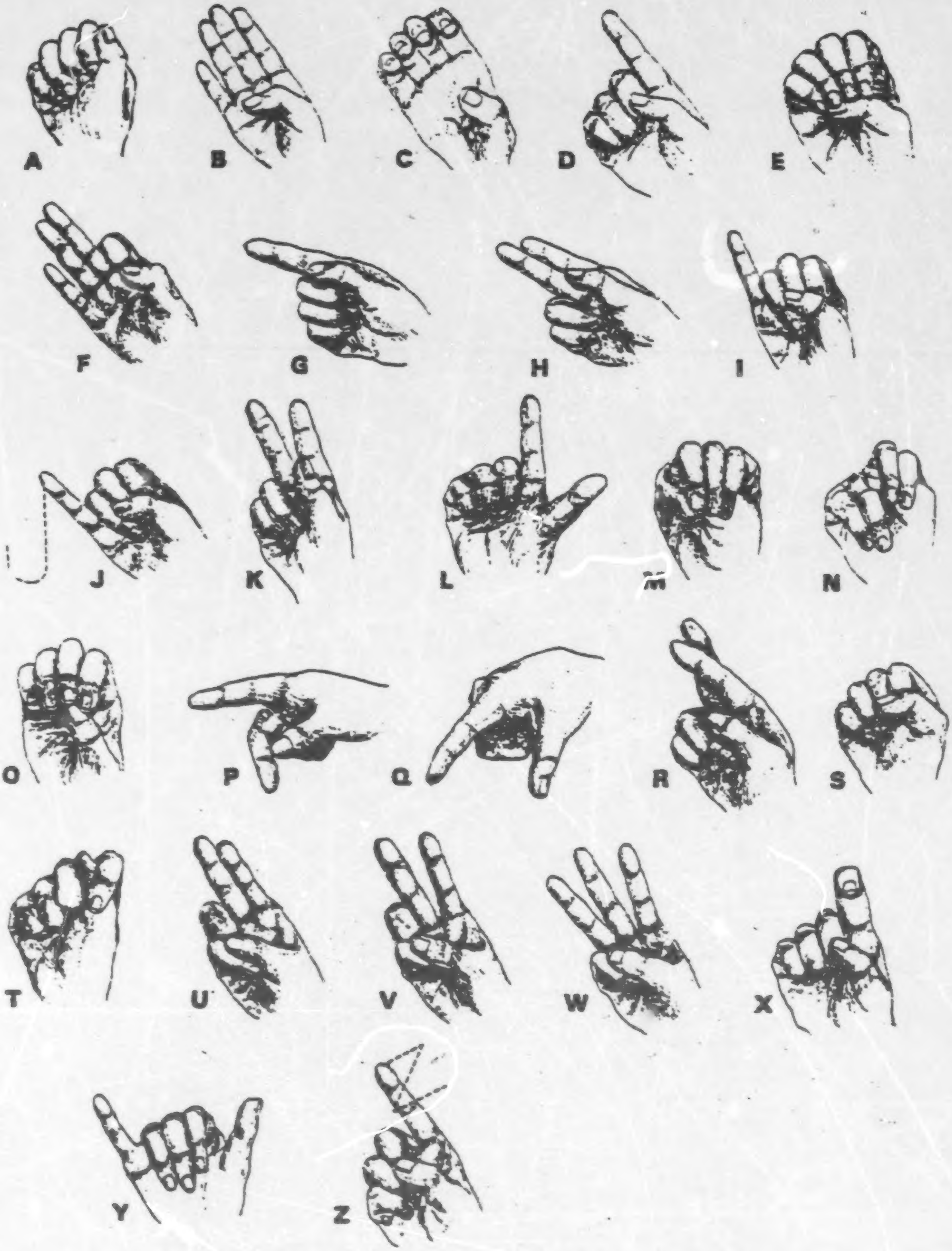
w. Noticing what is missing in a drawing.

x. Copying a color pattern that is out of sight.

y. Playing card games such as "Concentration" or "Go Fish."

N. Conclusion

Praise and patience are critical factors to remember when encouraging people to communicate. The individual must have a need to communicate, a means of communication, something to "talk" about, and an audience that is responsive, supportive, and shares the pleasure of success.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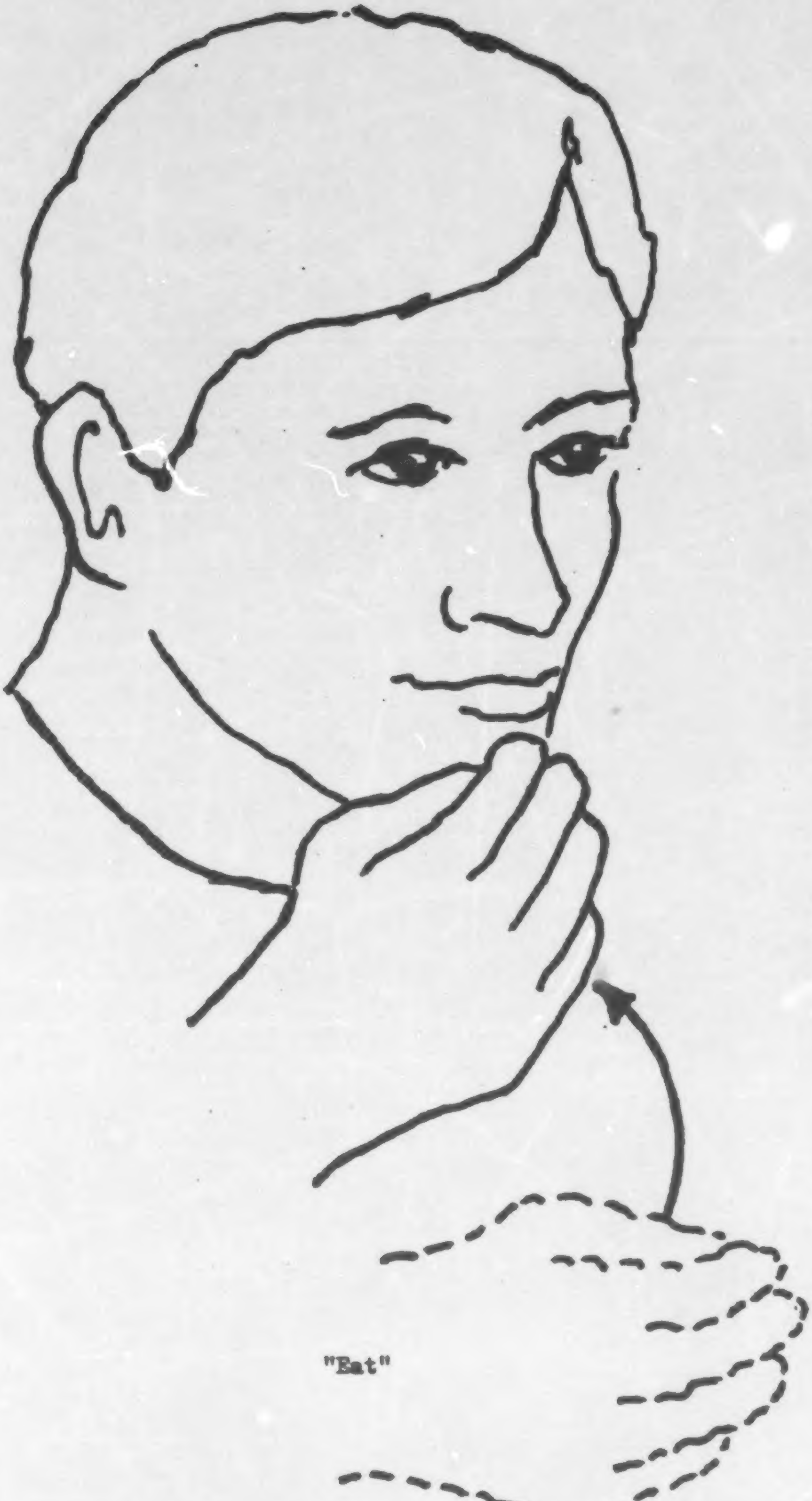
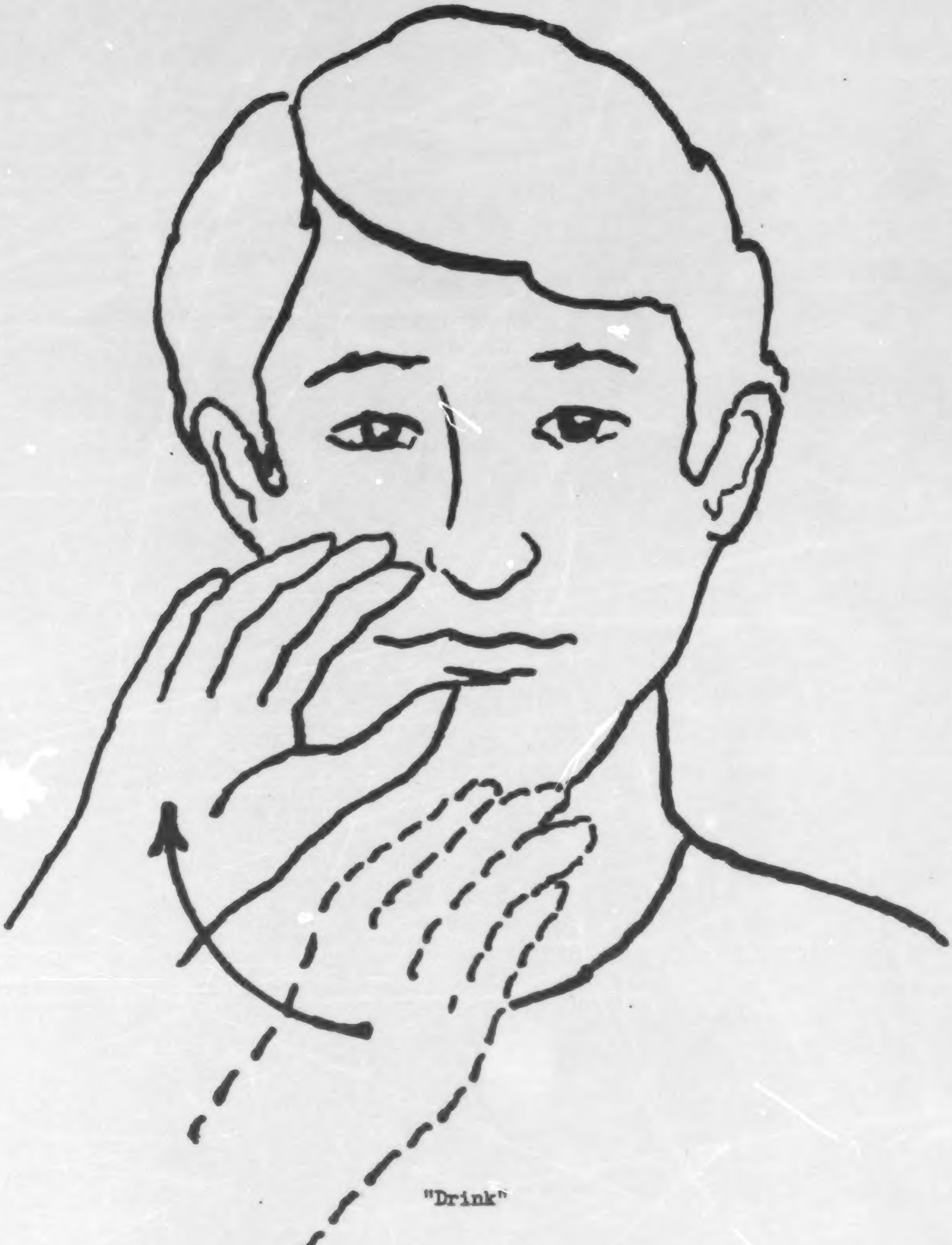


"Eat"



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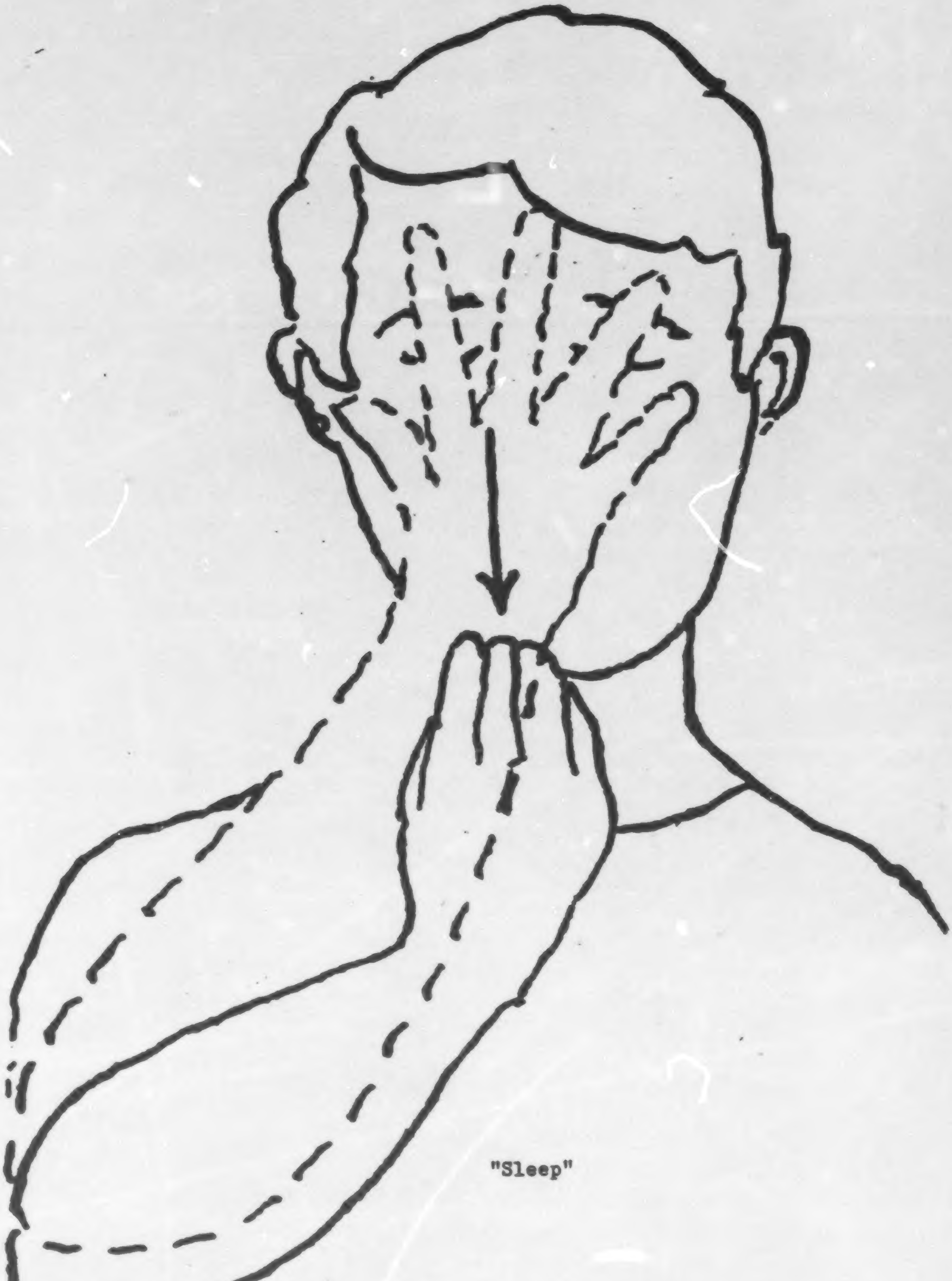
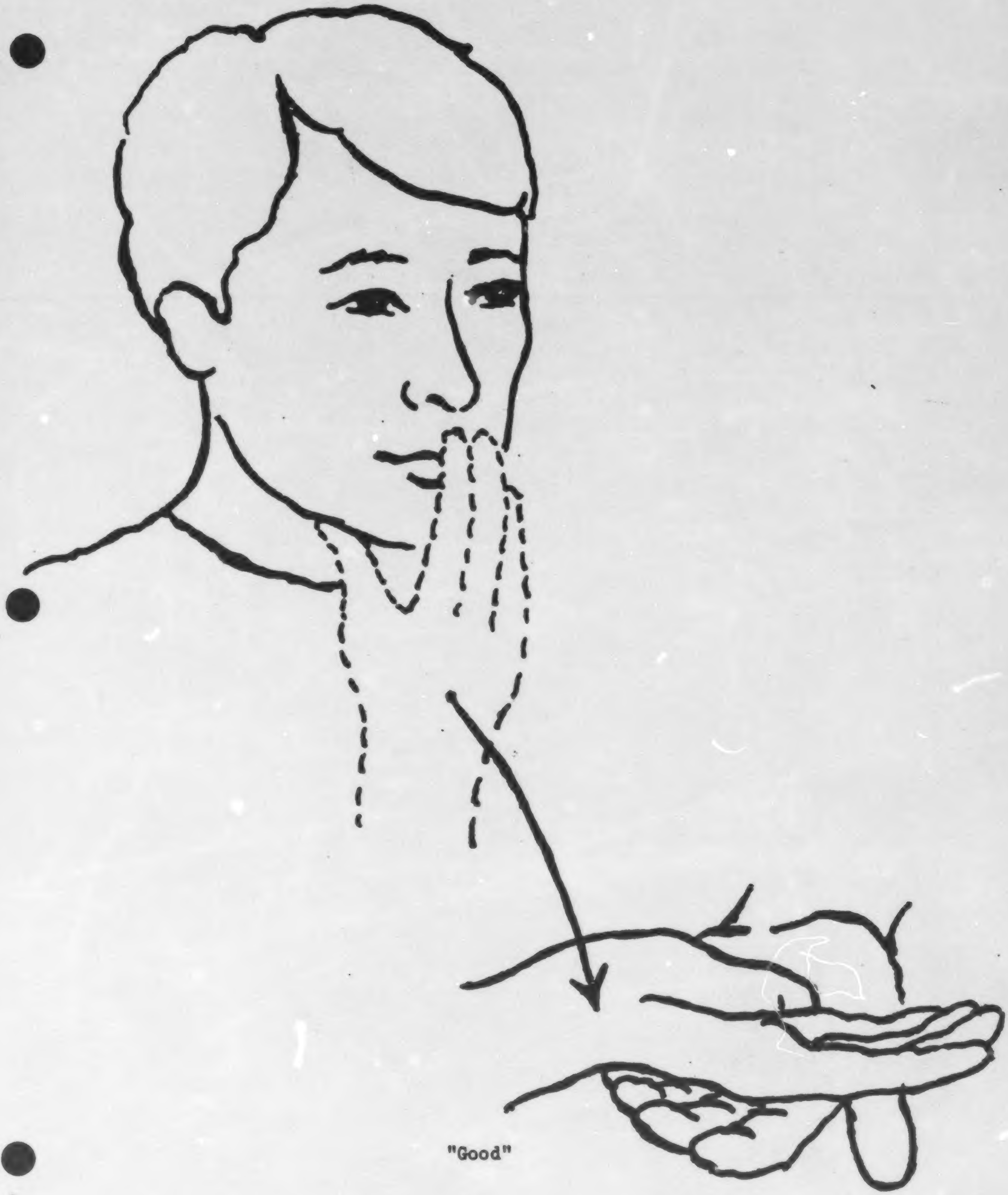
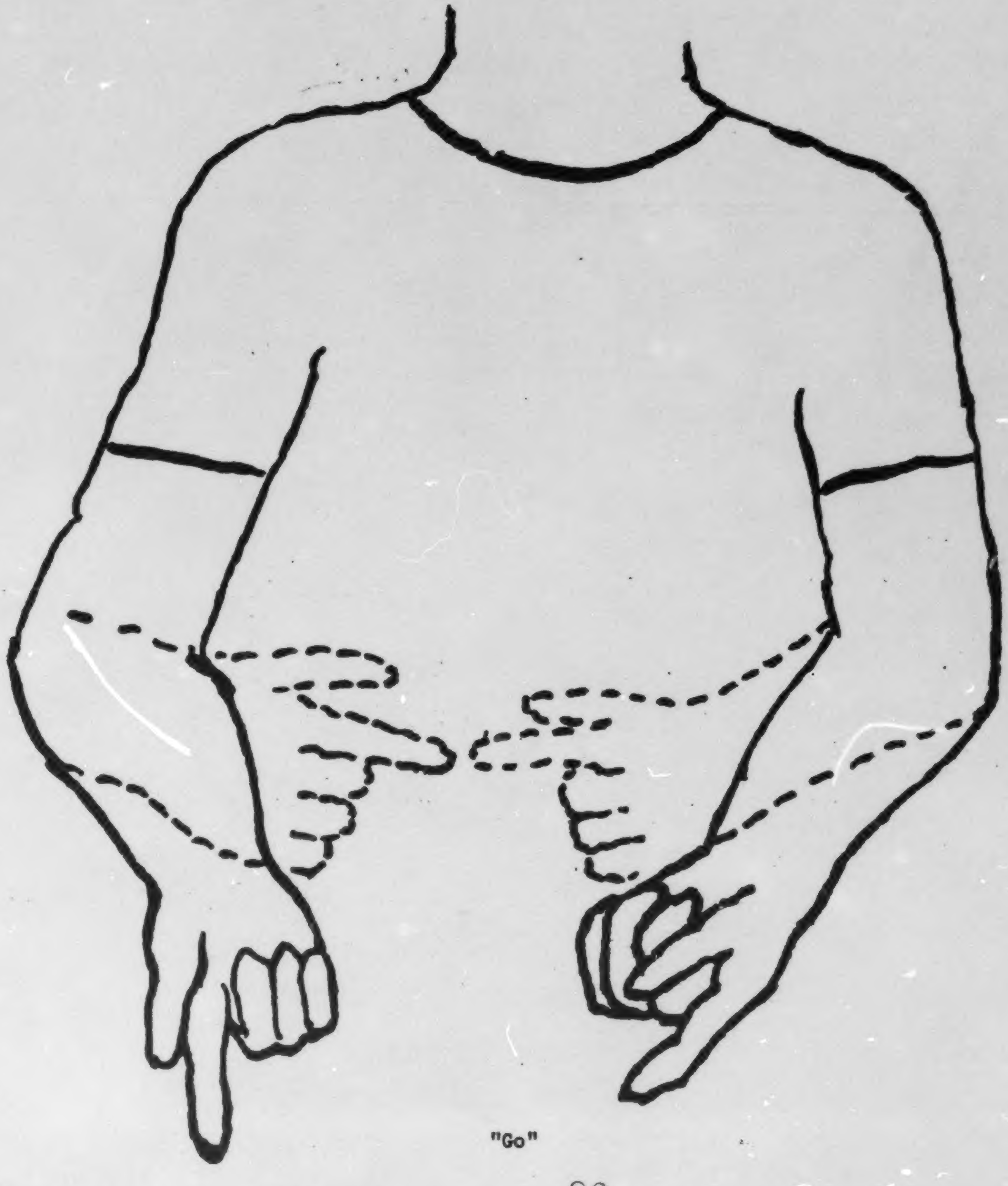


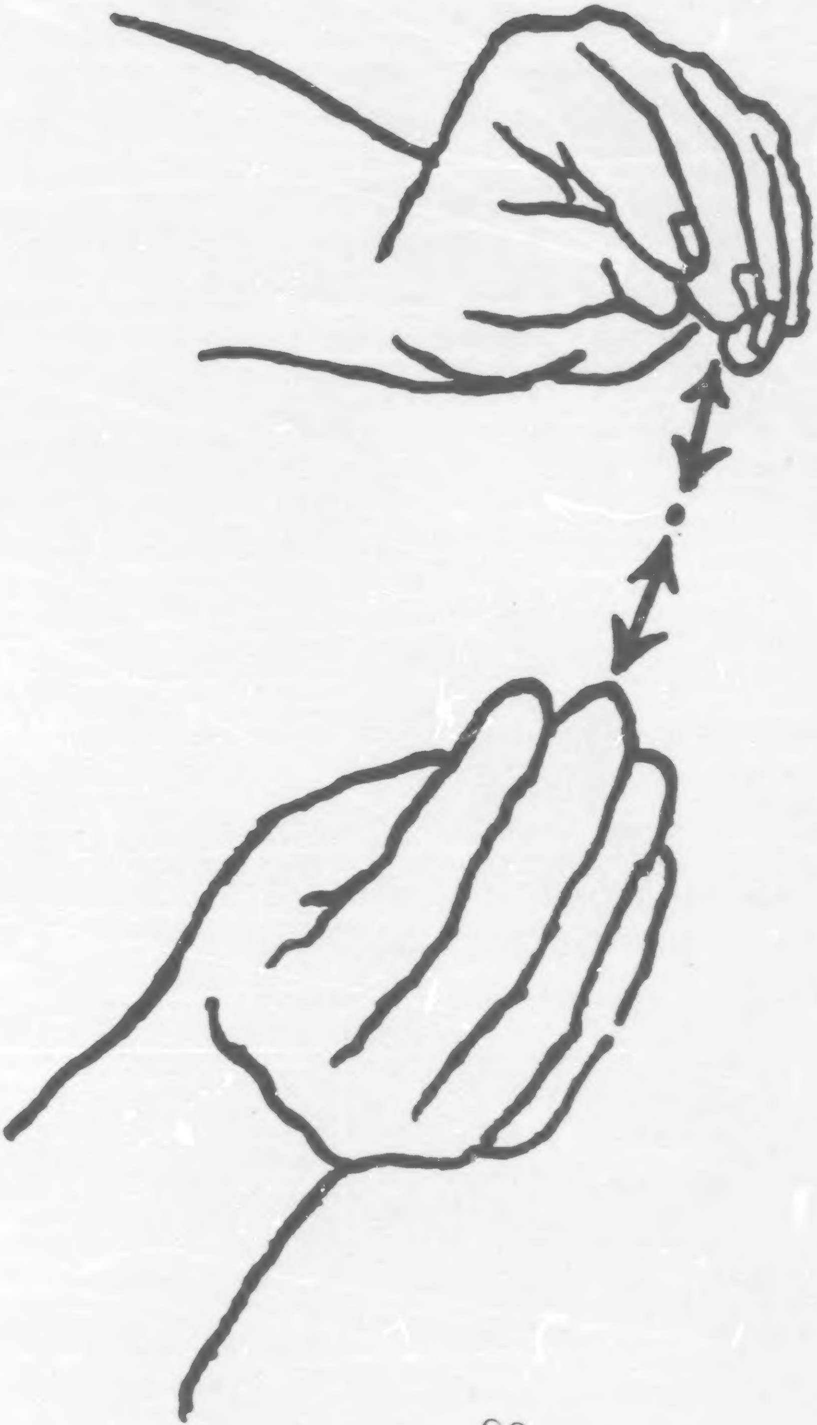
"Sleep"



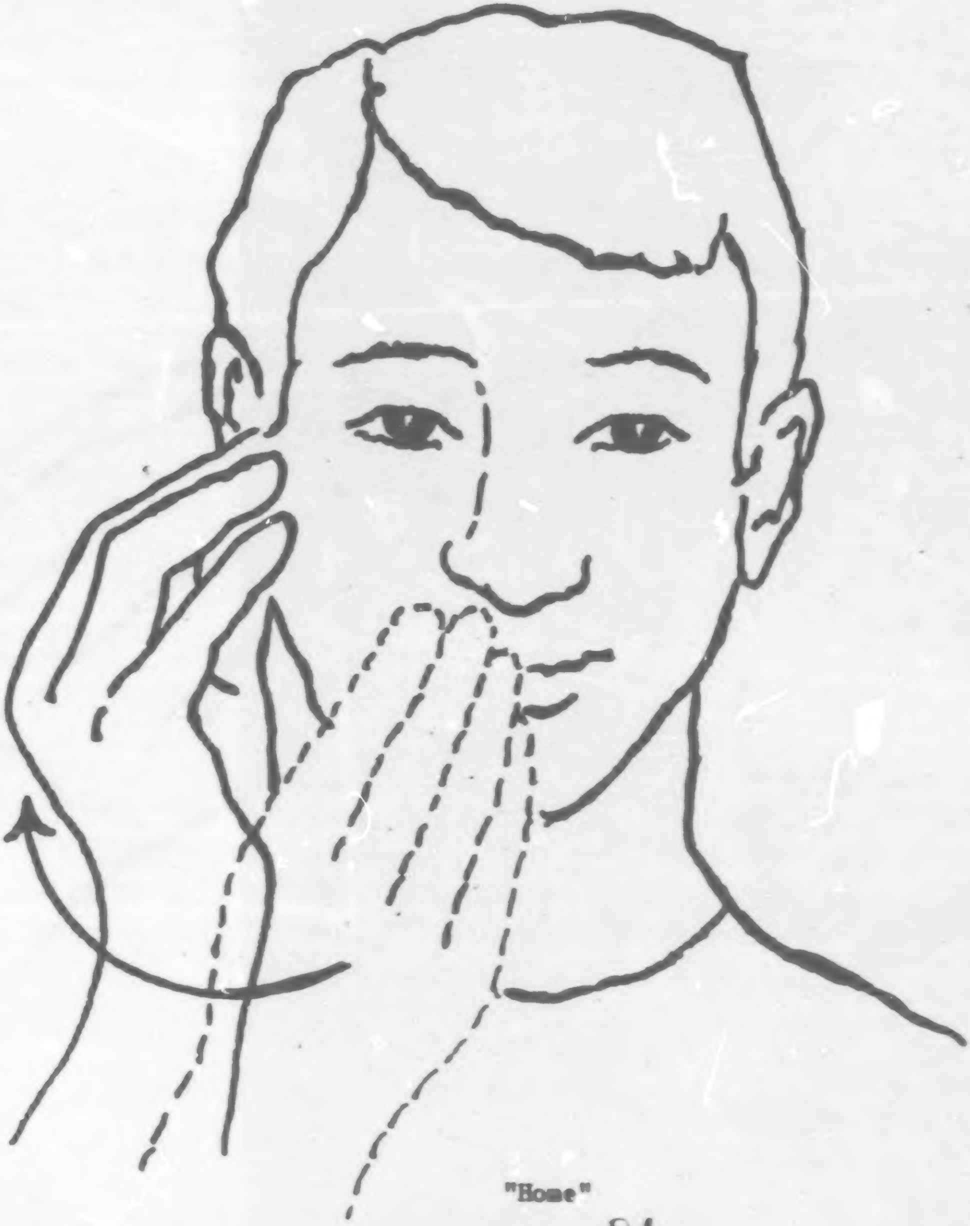
"Good"



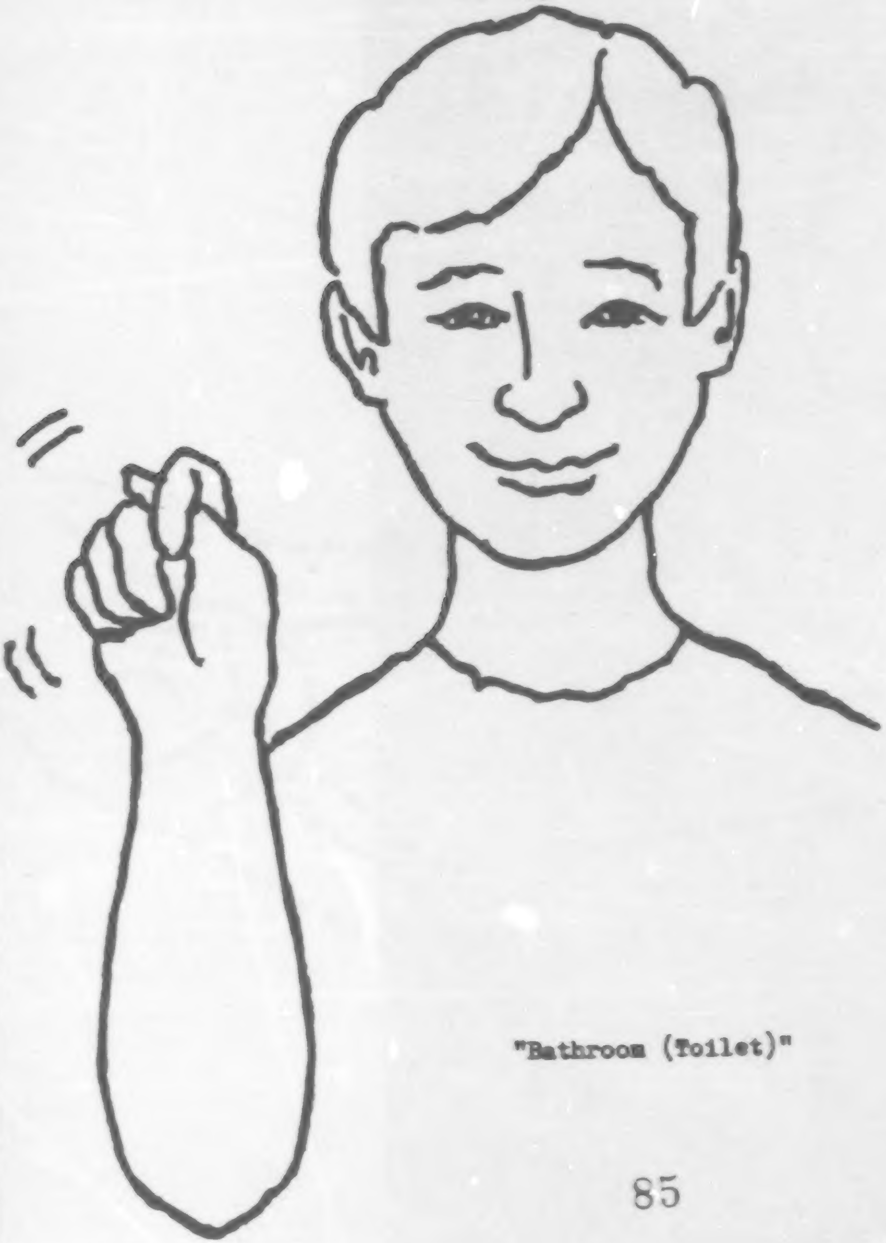
"Go"



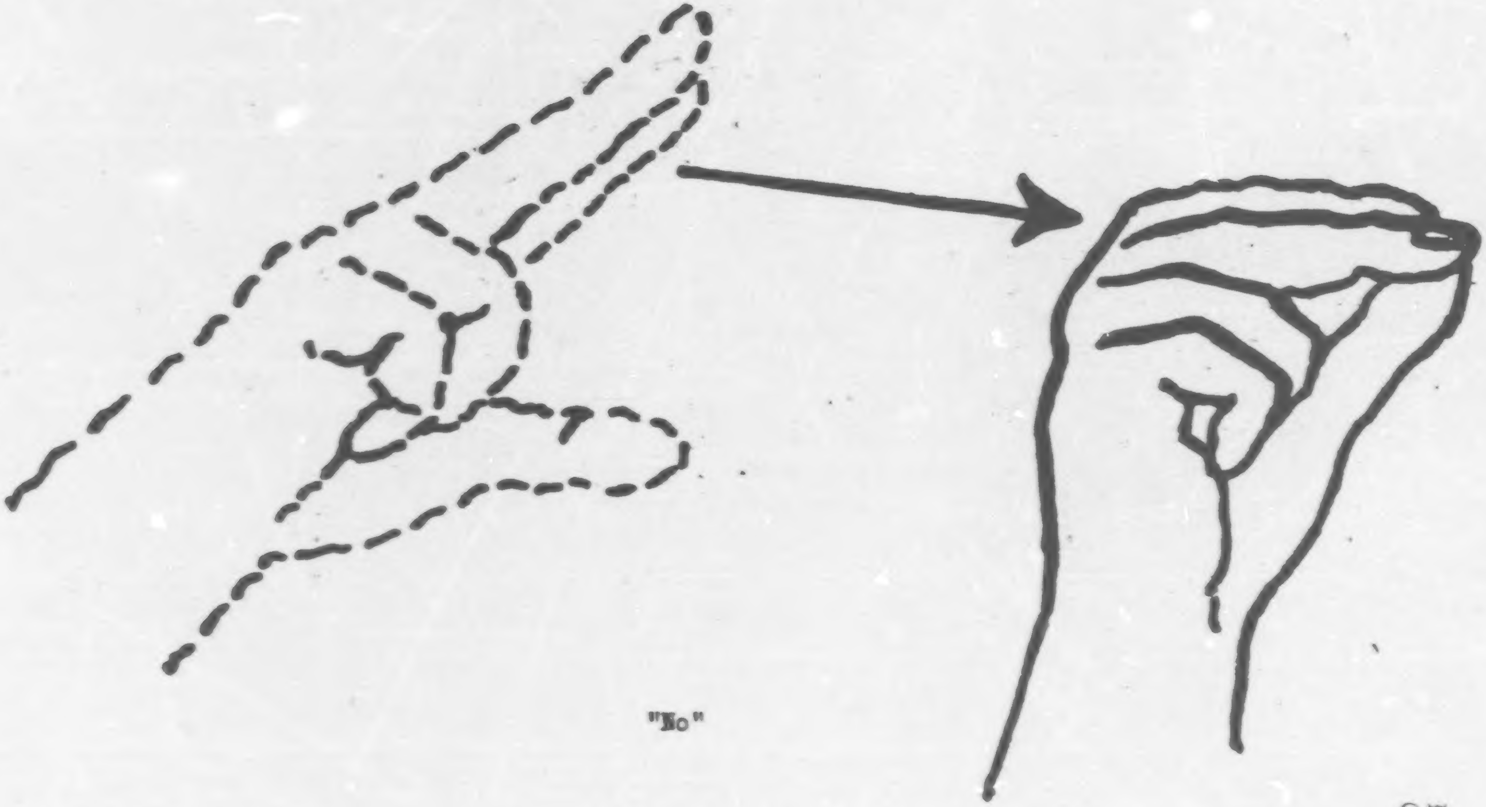
"More"



"Home"



"Bathroom (Toilet)"



"No"

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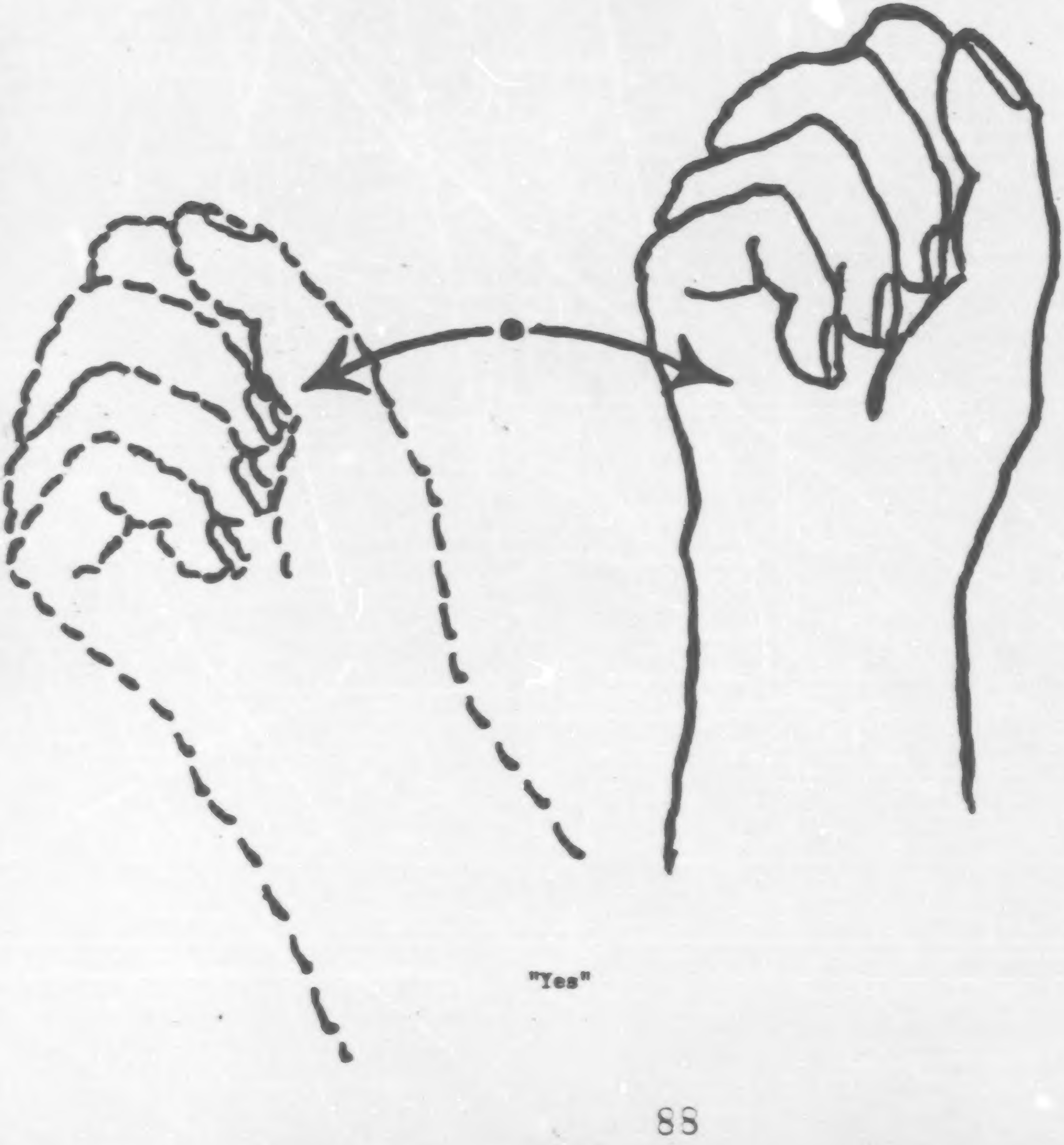
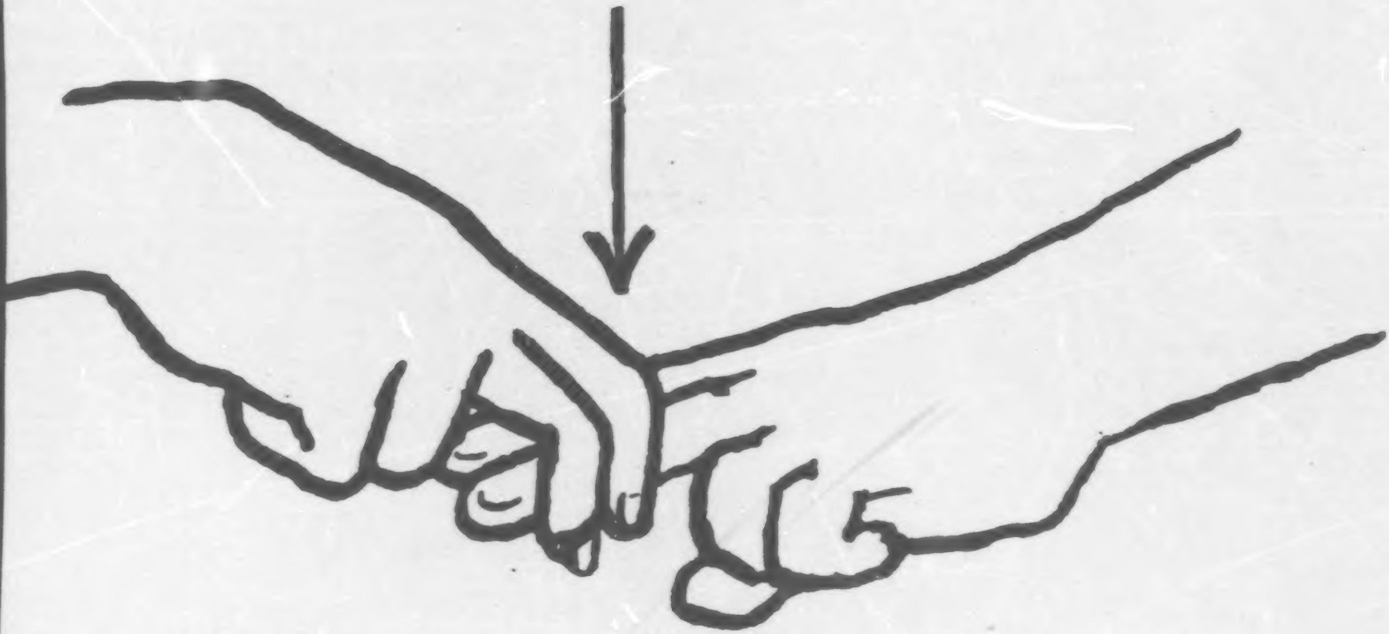
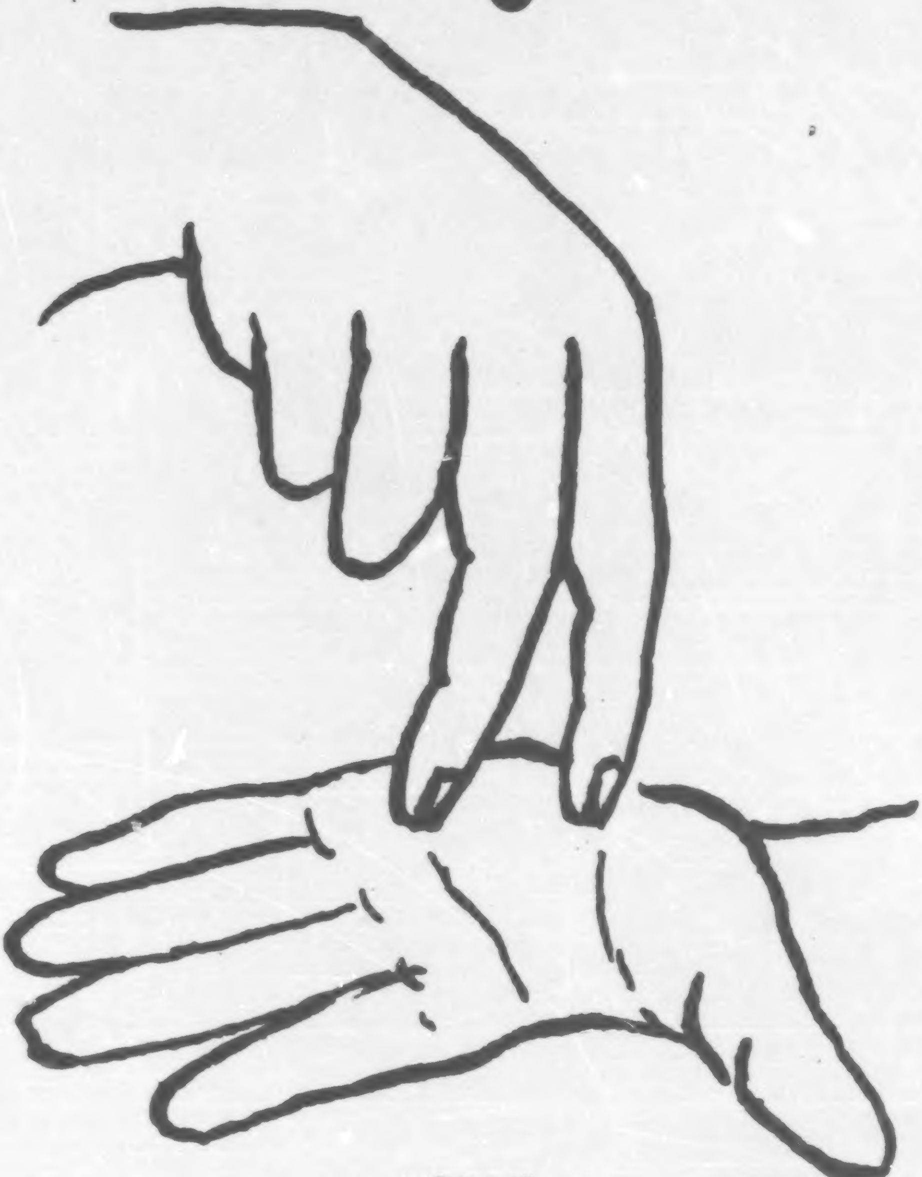


"Yes"



"Sit"



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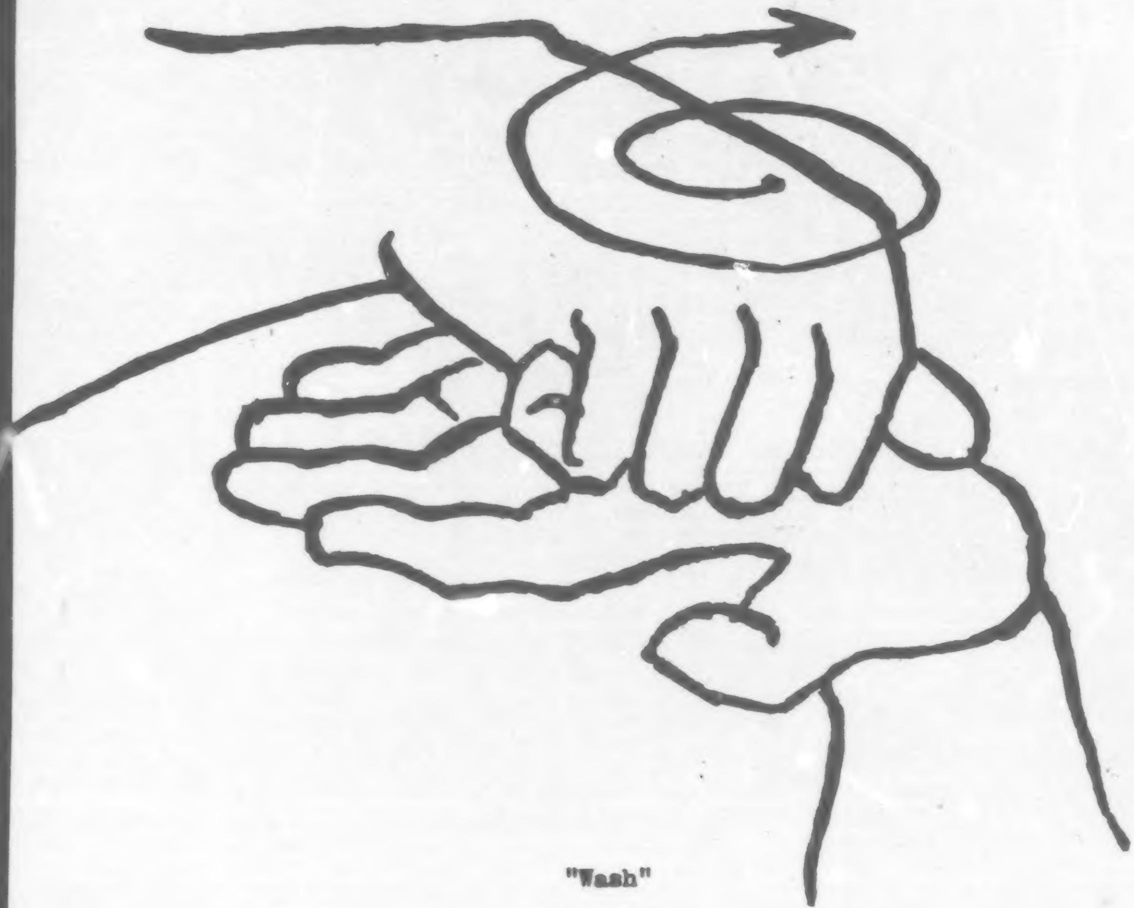

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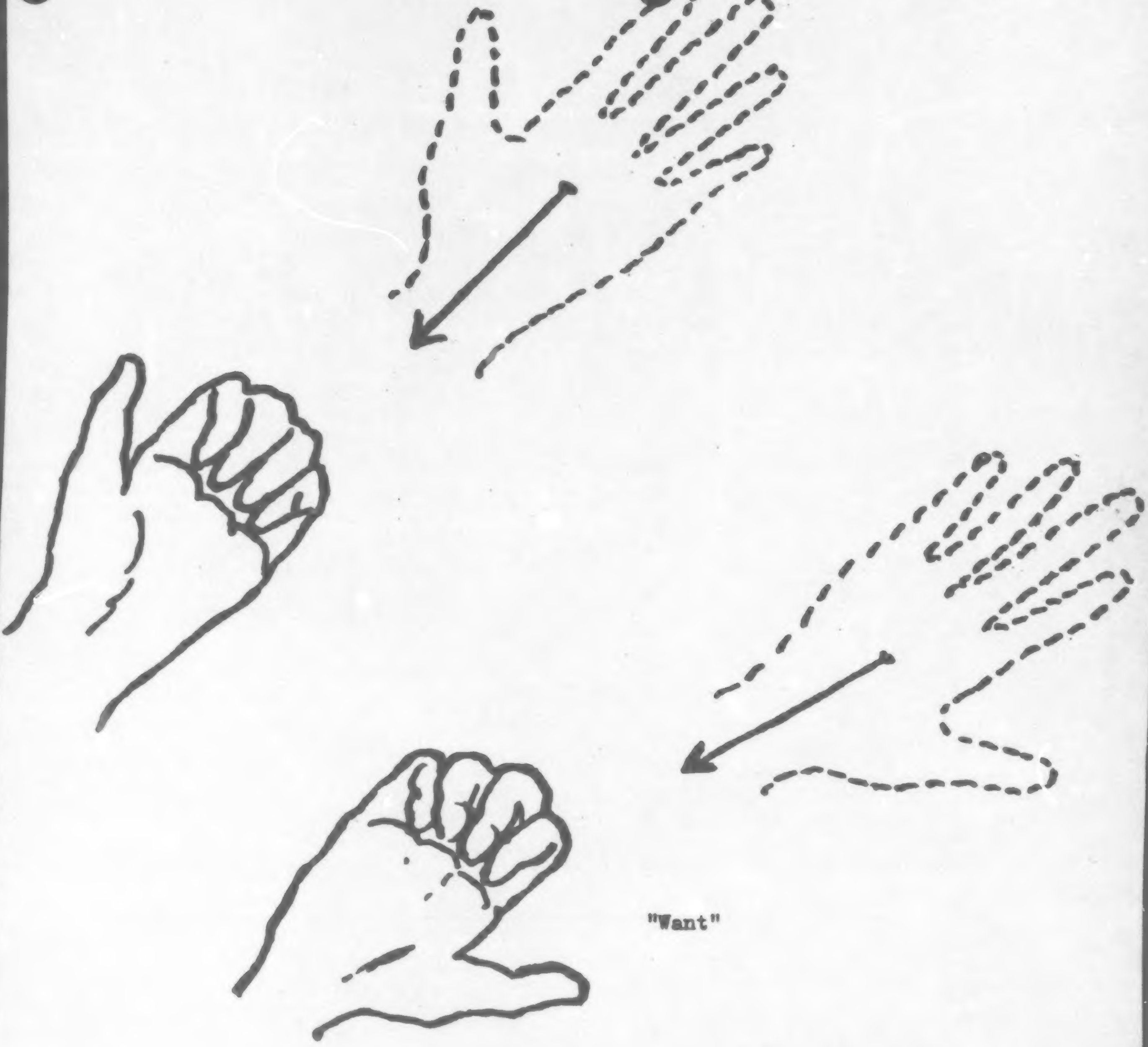

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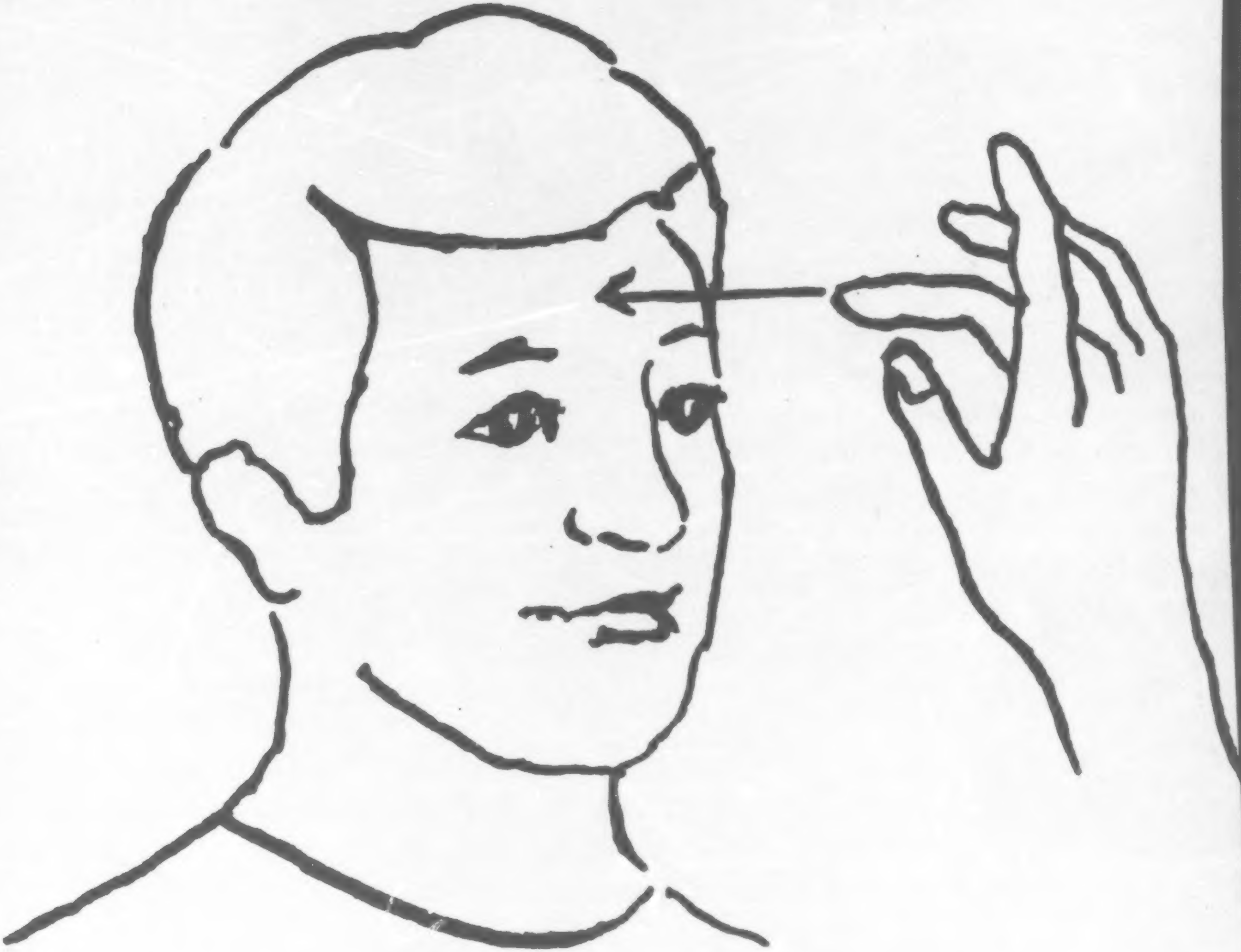

"Sick"

CHAPTER VIII: PHYSICAL MANAGEMENT AND ADAPTIVE EQUIPMENT FOR THE HANDICAPPED

A. Introduction

This chapter addresses the physical management problems that may be encountered by a respite provider who works with all kinds of people with special needs. Although the discussion is oriented toward the physically disabled person, the methods suggested will be useful in working with other handicapped persons. Many people require adapted methods in handling, but they may not need adaptive equipment. The sections dealing with lifting, transfers, and general principles of handling will be useful in a variety of situations.

B. Handling and Moving People

1. If you are working with a person who is unable to walk independently, you may be responsible for helping him get around safely. This may mean getting him into and out of bed, in and out of the bathtub, from one place to another in the house, or in and out of his wheelchair. If the person must be moved with the help of other people, this will require lifting and carrying. This section provides basic procedures for safely accomplishing this part of your job. During your training, you will also have an opportunity to practice the basic skills of transferring people.

2. How well prepared are you to handle this part of your job now? Answer the following questions.

   a. Are you concerned about protecting yourself from a back injury?

   b. Do you know at least one rule for good lifting?

   c. Do you know five rules for good lifting?

   d. Do you consistently use the rule(s) you know for lifting heavy boxes and other heavy items?

   e. Do you know the maximum weight you should lift alone?

   f. Do you ask for help when something seems too heavy?

   g. Can you do an assisted transfer with a person who can take some weight on their legs?

   h. Can you do a two-person lift?

   i. Do you know what steps must be taken before moving a person from one place to another or from one piece of equipment or furniture to another?

   If you could not give a "yes" answer to all of these questions now, you should be able to after completing this chapter.

C. How to Get Rid of your "Superperson" Image

1. Not many of us have the strength of a super hero. However, if you do not hesitate to pick up and try to move large pieces of furniture or heavy boxes which sometimes prove too much for you, your secret image of yourself may be closer to superman or superwoman than you think. This makes you an even better candidate for back problems resulting from lifting persons who are too heavy for you alone to carry. Remember there is nothing in the word "child" that guarantees the person is going to be light as a feather; there are heavy children. A child or adult who is very physically handicapped and cannot help by holding on and shifting weight for better balance will prove more difficult to move than a person of comparable size and weight who can physically assist.

2. Overestimating your own strength also puts the person at risk because you may find you cannot hold his weight long enough or may not be able to keep your balance with too heavy a load. As a result, both of you could land on the floor or against the edge of some furniture. The rule of thumb is not to lift a person by yourself who is more than one-quarter of your weight. (Robinault, 1973). However, if you are lifting a person and you lose your footing or balance, do not try to catch the person in mid-air. You can help brace the fall by helping the person and yourself to the ground.

D. Learn to Ask for Help

1. Do you consider yourself an independent, self-sufficient person who prefers to do things yourself and doesn't like to ask others for help? Perhaps you don't like to wait around until someone is free to assist you. Although independence is generally an admirable trait, it could prove unsafe in cases where lifting a person should not be done alone. Try to plan ahead so that you know there will be someone around to assist you when you have to make a major move, e.g., from the bathtub to the wheelchair. Remember, you are not asking help for only yourself; you're also asking help for the person who needs a comfortable, safe transfer.

E. Basic Considerations and Rules for Wheelchair and Stroller Management

1. Many handicapped people need or use special equipment for moving from place-to-place. Some may use a wheelchair; others may be moved in an umbrella stroller; still others will move using different toys, e.g., trikes.

2. Parts of the wheelchair. The major concern should be to identify those parts on any given wheelchair which may be removable--and thus may come loose in handling.

   a. Wheelchairs are made in a variety of models including those that collaspe or recline and those that are electric. Respite providers should ask parents for specific considerations in handling their wheelchairs.

3. Handling. First of all, you should consider--and remember--that a wheelchair is, in a sense, part of the person who uses it. It is a substitute for legs that cannot support and move a person's body. Thus, the wheelchair should be treated well and with respect--kept clean and in good repair.

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a. The respite provider should also remember that the handicapped person may have some ability to self-propel a wheelchair. Although sometimes tedious, the handicapped person should be encouraged to maneuver his/her wheelchair when possible.

b. If the person is unable to propel the wheelchair independently, you should follow these basic principles of management:

   i. Offer to help.

   ii. Always make sure seat belts are fastened.

   iii. When stopped, brakes should always be locked.

   iv. When pushing the wheelchair, use both hands on the grips. The only time you may need to use one hand is when going through a doorway--you may need to hold the door open with one hand and push the wheelchair with the other hand.

   v. If the handicapped person has involuntary (uncontrolled) movements, especially of the arms, use caution when moving through narrow spaces, e.g., doorways. It may be helpful to hold the person's arms gently so a flailing arm isn't hurt by banging the door frame.

   vi. Be careful not to push the wheelchair too fast; for many, this is extremely frightening. Try to maintain a normal walking pace.

   vii. Curbs: when going down, turn yourself and the wheelchair backwards. Gently ease the large rear wheels down the curb to the street; tip the chair slightly to allow front wheels to touch the street. When going up, the chair should be in front of you. Tip the chair just enough for the front casters to clear the curb; lift the rest of the chair up onto the sidewalk. Depending on how steep a ramp is, you may wish to bring the person down with the wheelchair faced backwards.

   Note: Although it may seem easier to tip the chair and roll it up or down the curb in front of you--DO NOT--this can be extremely dangerous if the handler loses footing or grip!

4. Other Mobility Aides

a. Some handicapped people may use other equipment for mobility, e.g., walkers, jumpers, or tricycles. The precautions for use will vary from person to person. Specific questions should be asked about how long a person should be allowed to use a mobility aide as well as any special considerations for use, e.g., support belts, foot loops.

5. Proper Lifting

a. If you were asked: What is the proper way to lift large and/or heavy objects? Most of you would probably reply with something like this, "Lift with your legs, not with your back; or bend at your knees, not at your waist." How many of you always follow that rule? Not many of us are always as conscientious about these things as we should be. If we are lucky enough never to have injured our back, we have family or friends who have strained their muscles, popped a disk or in some way injured their backs. Back pain is no fun, and it may cause a permanent curtailment in the kinds of things you are able to do.

b. Since your job may require that you do more lifting than you usually do, you must follow these procedures for lifting at all times.

c. The procedures listed below are recommended by Davis:

   i. Spread feet apart to provide a wide base for better balance.

   ii. Bend at knees.

   iii. Keep back straight.

   iv. Tuck in chin.

   v. Grip with the Palmar grasp--that is with your whole hand, as opposed to grasping with your fingers.

   vi. Do not turn or twist your body.

   vii. Keep the load close to you.

6. Transfers

a. A transfer is a method used to move from one surface to another (such as from bed to wheelchair) when a person cannot stand and walk there safely and independently. There are people whose legs are paralyzed so that they can't use them for walking but they are able to use their arms to move around on instead. Their arms are strong enough to allow them to take their entire body weight just as our legs do. They can use an independent transfer to move from one place to another. There may be selected situations in which you will need to supervise them or to stand by to help them. This is called a supervised transfer. If a person needs more help, then you will use either an assisted transfer (person can help in someway) or a passive transfer (person doesn't help and you do all of the work). It is important to find out how much the person can help in the transfer. You can ask the parent(s) and/or the person you are assisting how much help they can can provide, and then encourage them to help as much as possible.

b. People vary in the degree to which they can assist. Some will barely take their own weight, while others will accomplish most of the transferring themselves with a little assistance from you. For example, if the person cannot walk but can take their weight on their legs, they are able to assist you when you move them. This is called an assisted transfer. If the person is unable to take weight on his legs or buttocks, or has a tendency to get very rigid or collapse unexpectedly, you cannot expect him to help you. This requires a passive transfer because they can't take an active part. In other words, they must be carried when moved from one surface to another, e.g., from floor to chair. Depending on the physical involvement and size of the person, you may either do a one-person or two-person passive transfer or carry.

c. There are also pieces of equipment which may assist you to lift the person. Sometimes this equipment substitutes for one or more persons who would ordinarily be required to help. One piece of assistive equipment is the transfer board. This allows the person to slide in a sitting position from one place to the other, e.g., from the bed to the wheelchair. In this way, they do not have to stand at all. This is generally used with just one person assisting in the transfer and does not require a lot of lifting. A second piece of equipment which is used for heavier children, and particularly for larger children with musular dystrophy, is the mechanical lift. This will take some practice to use efficiently. If you are to use one, have the parents show you how to do it and then have them observe you doing it until you both feel comfortable with your ability to operate it. These devices take a little time to use but provide valuable assistance for the heavy person who has to be carried.

d. The type of transfer used must fit the particular situation, i.e., moving from the floor to the wheelchair vs. moving from the bed to the wheelchair, as well as the physical involvement and weight of the person. You need to discuss and learn the appropriate lifts and transfers with the parent(s)/person you're assisting. The following guide shows a number of possibilities.

F. General Procedures for Transferring

Question	Yes	No
1. Do you know where you are going?	Proceed to Step 2	Decide now so you do not end up carrying the person looking for a place to put him/her down.
2. Do you have a clear path so you do not have to climb over or squeeze between?	Proceed to Step 3	Move as many obstruction as possible.
3. Have you equalized the heights between the two surfaces as much as possible	Proceed to Step 4	Equalize heights of the two surface as much as possible.

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4.	Is the furniture or piece of equipment stable so it will not slip when you try to move person into or onto it?	Proceed to Step 5	Push up against wall or other stable surface to secure.
5.	Do you have enough room to be able to follow the proper lifting procedures?	Proceed to Step 6	Rearrange space you are working in if possible.
6.	Is the surface from which you are taking the person positioned so that it is as close as possible to the surface you are moving him to?	Proceed to Step 7	Re-adjust distance and/or angle between two surfaces.
7.	If the person has a weak side, have you arranged things so that he will be moving in the direction of his stronger side.	Proceed to Step 8	Reposition person to surface to which he is moving is closet to his stronger side, or reposition chair/wheelchair so that it is located close to stronger side.
8.	Are you using the most advantageous transfer procedure for this situation?	Proceed to Step 9.	Reconsider how much the person can assist and the relationship between the two surfaces with regard to height and distance.
9.	If a wheelchair or a piece of equipment with brakes is involved, have you or the person locked these?	Proceed to Step 10.	Lock Brakes.

10. If necessary have you lifted the wheelchair footrests and taken off wheelchair armrest?	Begin your Transfer	Pull-up foot rests to get out of way. Take off arm rest on side to which are transferring.

G. Two-Person Lift and Carry

When using the two-person lift, it is easiest if one person lifts the upper part of the body while the other lifts the lower part. A person should never be lifted by his arms and legs alone. If you wonder why, have two people lift you, each on one side, using only your arms and legs. It isn't very pleasant.

H. Adaptive Equipment and Positioning

1. Some people with physical handicaps use adaptive equipment. This equipment has been designed or prescribed for the person to help him or her with a special problem, e.g., the inability to sit in a regular chair. There are many different kinds of adaptive equipment. There are pieces of equipment which help the person to feed himself, dress himself, sit-up, stand-up, etc. The adaptive equipment discussed in this chapter pertains to the proper positioning of the person in the home. Adaptive equipment used in feeding and dressing will be covered in other chapters.

2. Adaptive equipment used for positioning can be divided into three categories:

   a. Common items which are used in an uncommon way. For example, a person may lie on his stomach over a furniture bolster or wedge to encourage him to lift up his head and to bear weight on elbows or hands.

   b. Common items which have been altered especially for the person. For example, an ordinary chair may have pieces of foam and straps attached to help the child sit in it.

   c. Uncommon pieces of equipment which have been designed especially for the handicapped person. For example, the prone board allows the person to bear weight on his legs while it frees his hands for activity.

   d. You will be concerned with the following positions:

      i. Lying Down:

         (1) On stomach

         (2) On back

         (3) On side

      ii. Upright:

(1) sitting

(2) standing

iii. Although you can easily change from one position to another, there are people who can't. They may be totally dependent on you to help them move from one position to another. Think how it must feel to spend the whole day on your back looking at the ceiling with your arms at your sides. Inability to move results not only in physical discomfort but can cause further physical problems such as skin breakdown.

I. Guidelines for Using Adaptive Equipment for Positioning

1. Find out from the parent if there are any positions in which the person should not be placed.

2. Check frequently to make sure the person is still in the appropriate position, and is not uncomfortable as a result of movement.

3. Post a checklist of positions to be used and indicate how frequently the position should be changed. Consider that 20 minutes in a wheelchair by a person with little or no voluntary movement equals about 3 hours of your time spent sitting in one place (Finnie, 1974). Try to move the person every 20 minutes if possible.

4. Check off each time the person's position is changed.

5. Find out from the parent how often the person should be moved when sleeping.

J. Braces and Splints

a. Braces provide support and aid in prevention of deformities. There are a variety of braces and splints, each designed with a specific purpose. Be sure to ask parents for specific instructions about how to put on braces and splints, and ask about the appropriate tightness of fit. Braces that are adjusted too tightly may cause pressure sores; these ulcers form beneath the skin and are difficult to detect until advanced stages. In addition, people with lack of skin sensation/sensitivity may not be able to detect the pain of developing pressure sores. Note the amount of time braces/splints are to be worn, and make sure that physician's time allotments are followed. This information should be obtained from the parents.

K. Questions to Ask Parents

1. Does the child/adult use a "mobility aide," e.g., wheelchair, walker, jumper, trike?

   If "yes":

   a. For what length of time may the person use the device?

b. Are there special precautions/arrangements/positions used for placing the person in or removing him or her from the device?

c. Can the person propel the device alone or is assistance needed?

d. If wheelchair: 1) are there any removable parts? 2) any precautions in handling?

2. Does the person wear braces and/or splint?

   If "yes":

   a. For special activities? All waking hours? Or given time period?

   b. Any special procedures for putting on brace/splint?

   c. How tight should the brace/splint be fastened?

3. When the person is lying on the floor or in bed, what position(s) are best?

4. Should the person be allowed to "weight bear"--stand or attempt to stand or move in the walking position?

5. Are there special considerations in moving (transferring) the person from:

   a. Bed to chair (and return)?

   b. Chair to floor (and return)?

   c. Chair/floor to toliet (and return)?

   d. Wheelchair to standard chair (and return)?

   e. Into/out of car (bus) seat?

   f. Into/out of the bathtub?

6. Is the person being seen by an occupational therapist? (O.T.)

   If "yes":

   a. has the O.T. made suggestions for activities, self-help skills, or use of adaptive devices which are being carried out in the home?

7. If the person being seen by a physical therapist? (P.T.)

   If "yes":

   a. Has the P.T. made suggestions for positioning, exercises, or use of adaptive devices which are being carried out in the home?

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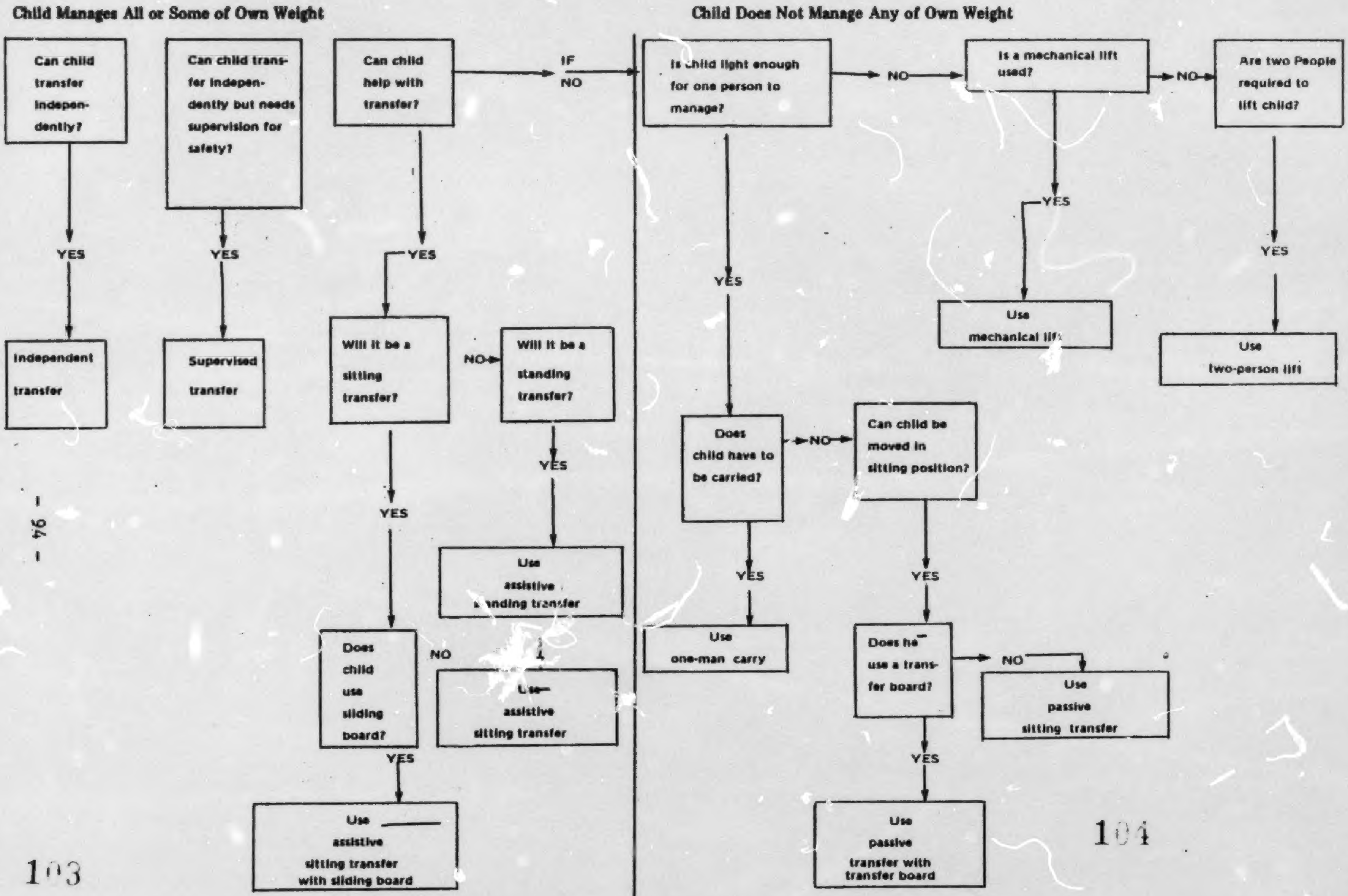
HOW TO CHOOSE APPROPRIATE TRANSFER


Child Manages All or Some of Own Weight
Can child transfer independently?
YES
Independent transfer
Can child transfer independently but needs supervision for safety?
YES
Supervised transfer
Can child help with transfer?
IF NO
YES
Will it be a sitting transfer?
NO
Will it be a standing transfer?
YES
Use assistive standing transfer
YES
Does child use sliding board?
NO
Use assistive sitting transfer
YES
Use assistive sitting transfer with sliding board
Child Does Not Manage Any of Own Weight
Is child light enough for one person to manage?
NO
Is a mechanical lift used?
NO
Are two People required to lift child?
YES
Use two-person lift
YES
Use mechanical lift
YES
Does child have to be carried?
YES
Use one-man carry
NO
Can child be moved in sitting position?
YES
Does he use a transfer board?
NO
Use passive sitting transfer
YES
Use passive transfer with transfer board

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CHAPTER IX: DRESSING, GROOMING, TOILETING AND HOMEMAKING

A. Introduction

1. As a respite care provider you will be asked to enter into the family routine and yet not be a family member. At no other time will you be required to become more closely involved than when working with handicapped persons as they dress, groom, toilet, and live at home. You will have much of the responsibility of a parent but without complete authority.

2. During these times, providers must be careful to be a part of the family's established routine. Be very careful not to "take over;" your role is temporary. Although you are extremely important, you will be gone shortly, and the parent(s) will again be the authority with the handicapped individual. You must use the techniques you have learned while carrying out your job within the established routine of the family. It is your job to observe and inquire about such routines; it is the parents' job to tell you about these routines.

3. There are times when you will not immediately understand the family's established practices regarding the child's care. Questioning the parent about what you see should help. Keep the lines of communications open.

B. Dressing

1. In the actual process of carrying out your job as a respite care provider, the circumstances, of course, will vary tremendously. For example, when working on dressing with a group of young adults living semi-independently you may be asked for advice on style, color coordinations, etc. On the other hand, when giving respite care for a weekend, the parents may give very specific instruction as to how and when to dress the child, even which clothes to use. It is not possible to cover all situations with some description of what to do. Here we will try to give general information and then supplement each section with a variety of ideas that may help prepare you for your work.

2. When dressing a handicapped person be aware of general body mechanics, that is, be careful of your posture when you're lifting or even helping to move someone. You can easily strain your muscles or otherwise physically hurt yourself. You may also easily unbalance a poorly coordinated or seriously handicapped person by lifting or placing him or her in an unfamiliar way. Be prepared! Some people, once you start to help, will completely relax and depend on your strength; others will extend arms or legs or push back and become rigid in their effort to help. When changing or putting on clothes, always be aware of body mechanics, both yours and the client's. Be aware of balance, posture rigidity and/or flexibility of limbs. Obviously, "Changing a big kid ain't the same as changing a baby." You will be reminded of this again in the section on toileting.

3. As mentioned earlier, you may be asked your opinion on clothes. Handicapped people deserve to be dressed as fashionably as any one else; advise accordingly on style, colors, appropriate dress for particular occasions, sizes and general appearance. More often, of course, your job will be to help the person put on already specified clothes. It is almost

always better, and allows a handicapped person greater dignity, if you help rather than do it for the person, even if it takes more time for them to dress themselves.

4. Special devices such as leg braces, ostomy bags (a bag that collects body waste products such as urine or stools through an opening in the abdomen), etc., are usually put on first, so that the clothes go over them. The clothing should be loose. Be careful to pull the clothes gently over or around the devices so that the devices and clothing are in position. It is also important to remember to be careful with hearing aids and eye glasses. When everything is on, try to make a final check to see that laces, snaps or other closures are closed firmly but not pinching. If you have a choice of clothing, the simplest is best; for example, if a female has an ostomy bag then a dress, bikini underpants, and knee-high sox will facilitate easier changing of the bag.

5. Remember: when you place a device or garment on a client in one position, it does not always fit when he or she changes positions. When putting a diaper on a quite mobile 15-year-old male, it is easiest to place the diaper on a bench or chair and then have the client sit on it. After spreading the diaper a bit and pulling it into position, pin it on only one side. Have the client stand while you keep the diaper in position, then, while he is upright, pull the diaper into its final position and pin it. The fit of the diaper is much different in the two positions; if the diaper is pinned firmly when the client is sitting it will usually fall down when the client stands.

C. Grooming

1. As you might expect, we consider grooming as part of dressing. The general approach will be the same. You are aiming at independence for the person, while working within a routine that may vary from being structured to very loose.

2. One way of grouping the ideas about grooming is under titles such as (1) hair, (2) skin, and (3) clothing. These groups are not all inclusive of the aid you will give or the problems you will face while grooming handicapped people, but they will serve as rather loose categories for us now.

    i. Hair. It goes without saying that cleanliness can help a great deal with many grooming situations. Anyone who is generally clean, with clean clothes and clean surroundings is less likely to "catch everything that comes along," is more pleasant to work with, and is probably happier with himself/herself. Although we will concentrate here on hair cleanliness, some of the hints will, of course, apply to other areas of cleanliness and general care.

        a. Whether helping the handicapped persons directly or advising them, be aware of types of shampoos and soaps used. Many allergic reactions, skin irritations, eye, mouth, and throat irritations and rashes are directly traceable to these agents. It is better to wash or teach the person to wash often, rather than use perfumed or highly advertised "essence" soaps and shampoos. Ivory or other pure soaps usually clean as well as the fancy ones; again, a little time spent in talking with the parents or the individual will usually give you a hint as to whether there is a problem in this area. You may wish to offer a simpler solution.

(b) During the actual practice of washing hair, there are some things to watch for. Be sure you have towel(s) available, that the water is the right temperature, and that you can "handle" the individual if he/she starts to get out of the tub or shower. This may include simply reassuring the handicapped person that everything is alright, or may involve the use of a systematic behavior program (see Chapter VIII). Regardless, before you begin this task make sure you are prepared to respond to a number of potential situations. Have a good supply of clean, warm rinse water available.

(c) There are several reactions that may occur during the washing of hair. Some people are afraid of the water on their face and/or in their eyes; they jerk away or try to move away. If you do not know how they will react, try clear water first, then try soapy water later. Check their eye closing abilities. Will they close on request? Will they keep them closed? Can they breathe through their nose or mouth without inhaling water?

(d) Water on the client's head may cause jerks or changes in position that will allow water into the ears, eyes, mouth or nose. This may "tickle" or otherwise irritate the handicapped person and cause him/her to further change position or become alarmed. Go slow if you do not know, try to anticipate, and be prepared by asking about these situations beforehand.

(e) In the case of head hair, style may give way to practically. For a female person clean hair and a stylish cut are the main considerations. Long hair on the head and face of males is not "out of style," and it does not call undue attention to the individual. It may be more appropriate for some to have clean beards rather than many shaving scratches, cuts or rashes.

(f) Special consideration needs to be taken of other body hair also. With the younger persons cleanliness will be the basic consideration. With older people there are other obvious concerns in addition to cleanliness. In the case of underarm care there is the question of deodorants and, with females, shaving. It may be more important to emphasize cleanliness and let smell and dryness take care of themselves.

(g) In the case of pubic heair, cleanliness is the important consideration. Here, however, we might also emphasize thoroughness. Since this part of the body is associated with sexuality and our society has many taboos and superstitions about it, caution should be taken to keep the functions separate. We are concerned here with grooming, in particular, about hair and skin cleanliness.

(h) If the person washes himself/herself, be sure he/she does a thorough job. Sometimes a long "soaking" shower or bath will help. Close observation may be important. It may be necessary to demonstrate to the individual how to spread his/her legs, to soap thoroughly in the groin and around the buttocks.

(i) With the older severely handicapped person, again, cautions about body mechanics and posture should be remembered. Be prepared before you start. It may be very reasonable for the respite care provider to put on a bathing suit and get right into the shower. Of course, a bath in a tub has other advantages (i.e. soaking) and disadvantages (getting client in and out). Not all situations can be described, and our concern here is to give some considerations, cautions and hints, not to try to cover all.

(j) There are many situations which warrant special attention, such as someone prone to seizures or not aware enough to get himself/herself out of a dangerous situation. The bathtub is probably the most dangerous situation. Do not leave clients alone if there is any doubt about their safety.

(k) Be aware of the needs of menstruating females; get familiar with the woman's routine and find out how to help and where supplies are located.

ii. Clothing. Clothing should be current. They should not all be "hand-me-downs," but if they are they should be slightly modified if possible. Clothes should not all be the same color and style, yet they should easily be coordinated. Just because pull-on shirts are simplest and easiest to put on, you do not have to use only pull-on shirts. If necessary, sew a "button shirt" up the front, leaving room to pull it on, but leave the buttons so that it is a different style. Pull on pants with elastic waist bands are great for dressing, and they can be slightly modified for style by adding buttons or extra stitching.

(a) We urge simplicity, safety, and ease of care, but we also urge some consideration of style.

(b) Grooming is generally part of a routine. The routine may already be established, and the handicapped person may be able to carry out most of it with only minimal assistance. Others may be completely dependent on you for dressing and grooming. In either case "press-on with caution." Watch for helpful routines while trying to add pieces of your own that have been proven in other settings. To a large degree, personal dignity is related to grooming and each person should be encouraged to care for himself/herself as much as possible.

D. Toileting.

1. When toileting a handicapped person it is important to remember that easy access should be maintained and that physical assistance as well as special equipment may be required.

2. If the person is to be independent in toileting, he/she must be able to get to and from, and on and off, the toilet. For the person with a wheelchair the access doors should be wide enough, and there should be a wall or floor railings beside the toilet. The toilet area itself should be wide enough to accommodate a walker or a wheelchair. This is, of course, an ideal situation, and the provider must also be able to adapt to less ideal circumstances.

3. The size and height of the toilet should match the person's needs; the height of the toilet should be such that the person's feet are firmly on the floor. If the person feels insecure or off balance, he/she cannot relax enough to carry through the toileting. There may be a need for covered garbage cans, cleanser and tape for the person who wears an ostomy bag or urinary catheter drainage (a device to assist individuals who don't have voluntary control of urination). For the adult who is not totally trained, large diapers and rubber pants can be puchased.

4. The home aide should check with the parent for special instructions regarding changing areas for the smaller child, whether changing should be done on the floor rather than on a changing table.

5. A reward or reinforcer may be used for successful toileting. This could take the form of praise, a toy, a special food item, or candy. It is important to be consistent with this reinforcer so that the respite care provider should talk this over with the parent.

6. Care for the safety of the handicapped person and the provider should always be taken when handling a large person. Good body mechanics should be used when assisting a large handicapped person because he/she can easily get off balance. Always use the leg muscles rather than the back to do the lifting. It is wise to develop good habits from the beginning rather than to correct bad habits later on.

7. Developing good habits in the beginning is also useful in the routine of toileting. It is important to teach the more severely handicapped person cleanliness and the proper disposal of wastes. If this person has soiled himself/herself, then keep him/her from wandering off until he/she is cleaned. If the client is controlled a great deal of trouble can be avoided and personal dignity of each person is enhanced.

8. The parent and the handicapped person have usually developed a workable routine. It is the responsibility of the respite care provider to find out what this routine is and adopt it. It may not always appear to be the best way, but if there is good communication between the parent and provider a good toileting program can be maintained.

E. Homemaking

1. There are a number of different living situations in which you may work: family home, foster home, group homes, or individuals living alone or with roommates. It is important to remember in each situation that you are in someone's home and the routines and relationships that exist within that home should remain untouched. When going into a family situation try to keep to the family patterns. It may be necessary to sit down with a member of the family and ask them what the various routines are. Even though some of the methods may seem odd, do not let it bother you, there may be a very good reason for the way things are done.

2. Remember that most people have quirks--some people cannot stand dirty carpets, others get frantic if a nicknack is out of place--try to pick up on these habits and allow for them. It is also important to be aware of cultural differences. You should consider the different habits and diets that various ethnic or religious groups have. Once again, it never hurts to ask if you are not sure of a situation.

3. When working with handicapped adults who are living in the community on their own or together without supervision, it may be necessary to train these people in various homemaking skills. As with the family, you should be aware of personal relationships and various routines or schedules.

4. Be sure to keep the materials and equipment safe and simple, less is probably better. One all purpose cleaner for toilet bowls, floors, walls, sinks, etc., is better than teaching the person when and where to use several different types of cleaners. Remember that the ancient standbys, such as soda and vinegar are often as good as some of the commercial products, and they are safer.

5. Rather than teaching the difference between dirty-clean for all situations, it may be best to help set up a routine such as scrub floors on Saturday, laundry on Monday. Make the routine flexible enough so the handicapped person is not locked into it.

6. The placement of equipment and supplies may be an important consideration, particularly if the person is physically handicapped. If an individual is unable to reach the cupboards above the counter remember to place the vital necessities--dishes, foods, cooking pots--in the lower cupboards. The upper cupboard can be used for storage of seldom used objects or light weight, soft things such as towels that might be poked down with tongs. When working with the visually impaired be sure to leave materials where they are, if they are re-arranged tell the person immediately.

7. When teaching cooking skills remember to keep the menus simple. It is better for a person to become independent, even though it may mean a steady diet of raw fruits and vegetables, peanut butter sandwiches and TV dinners. If the person finds it difficult to handle the stove, for example, if they are in a wheelchair and cannot reach the dials, teach them to cook simple oven meals. If the stove/oven presents a danger it might be better to teach them to make sandwiches or salads. Remember some people will require special diets, either for cultural reasons or because of physical problems; be sure you find out about the dietary requirements of each client.

8. Most accidents happen in the home! Safety is particularly important when teaching home living skills to a client. Watch out for the use of electrical appliances around water, the placement of electric heaters, or the placement of furniture in relationship to baseboard heaters, overloaded plugs and extension cords, the misuse of electric blankets, frayed electric cords, collection of oily rags or any other combustible materials. Stress the importance of not mixing household cleansers (some mixtures of chlorine bleaches and toilet bowl cleaners create a fatal gas). When small kitchen fires occur, help the person to put it out properly by himself; remember do not put water on a grease fire. If there is an oven fire simply turn off the oven and shut the door. Always stress safe habits around gas, electricity and chemicals. And nag about not smoking in bed.

F. Summary

1. Grooming and homemaking tasks are excellent leisure time activities. It is a good use of time to spend major portions of the days including the handicapped person in planning what to wear, what to eat, and which housecleaning task to do. Have them take charge of some of these activities with you as an assistant under the direction of the handicapped person, even if this takes double or triple the time. Such activities are usually more satisfying for a handicapped person than watching TV or doing nothing!

G. Some Questions to Ask the Parents

1. Can the person dress herself/himself?

2. What is the proper procedure for dressing the person? Is help needed with all the clothing articles?

3. Are there special appliances that the person wears?

4. Where are the person's clothes kept?

5. Where do the soiled clothes go?

6. Is the person able to bathe herself/himself? If not how much assistance is necessary?

7. Is there a particular procedure for bathing? How often does the person bathe?

8. Are there any special materials or equipment needed when bathing? If so, where are they kept and what is the right way to use them?

9. How does the person get in and out of the tub? If lifting is necessary, what is the proper way to do it?

10. Does the person need help with any grooming, such as shaving? If so, what are the correct procedures?

11. Where are the person's personal grooming articles kept (toothbrush, comb, razor, etc)?

12. Are there any skin conditions such as allergies to watch out for?

13. If female, does she menstruate? If so, does she need any assistance with the sanitary napkin? What kind of sanitary protection does she use and where is it kept?

14. Is the person independent at toileting? If not, how much assistance is necessary?

15. Does the person have any "special" words connected with toileting or other means of communication?

16. Is the person on a toilet schedule?

17. Are there any special procedures that must be followed when toileting?

18. Are there any supplies or equipment that are necessary when toileting? If so, where are they kept, and what is the correct way to use them?

19. Can the person be left alone during toileting or should he/she be supervised at all times?

20. If the person is not toilet trained, where do you put the soiled diapers? Are there any particular problems in changing this person's diapers?

21. Does the person require or prefer a special diet?

22. Does the person have allergies to any food, or are there any foods the person must not eat for any other reason?

23. How does the person ask for food or drink?

24. What is the schedule for feeding?

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CHAPTER X: LEISURE TIME ACTIVITIES

A. Introduction

1. It has been said, "The whole end product of education is training for the right use of leisure" (Aristotle, 384 B.C.). Although the phrase, "leisure time" connotates carefree pleasure, its importance cannot be dismissed. Indeed, "recreation is a fundamental human need important to mental health because it provides a change of pace, an opportunity to be creative, a chance to meet and make new friends, an outlet for the emotions, and a change for relaxation" (Gardner, 1960). Leisure time is also important in promoting social, intellectual, and motor development. People need to discover which games, hobbies, crafts, and activities give them personal satisfaction so that there will never be an occasion when they cannot think of anything to do. Many of us seek professional assistance to develop the essential skills for our leisure time activities (golf pros, fishing guides, dance and yoga teachers, etc.), so the need for such instruction appears to be fairly universal. However, leisure time can become a liability, unless an individual has opportunities to use leisure hours in a satisfying, constructive form. Instead of happiness and freedom, leisure can also bring boredom and dissatisfaction, particularly if leisure experiences are frustrating or not appropriate.

2. Leisure time activities are even more essential for the handicapped individual. The handicapped need to participate in leisure and recreational opportunities for expanded growth to participate with the non-handicapped, and because handicapped individuals have a great deal of "free" time. Although society is finally providing more programs for people with handicaps, there are still many who are not taking advantage of these opportunities for their leisure time. Among the reasons some handicapped people are not participating in leisure time activities are that they do not know the rules or skills of the activities; they do not know where and how to find recreational activities in the community; their handicaps are so severe or profound they are unaware of their options; or they have had past failures with leisure time activities.

3. In this chapter you will learn how to introduce handicapped people to the importance of developing skills for use in recreational leisure time activities.

4. To begin with, remember one axiom: There is no kind of recreational activity that some handicapped person has not enjoyed!

5. The major difference between a program for the handicapped and a program for other groups will be reflected not so much in the type of activities as in the way these activities are adapted to the needs of each individual. A handicapped person is one who, because of developmental disabilities, cannot play, learn, work, or do all the things other people the same age can do. This can be due to mental retardation or due to crippling conditions such as cerebral palsy, epilepsy, dyslexia, autism, or auditory or visual impairment.

B. Where to Begin

1. A good way to begin thinking about leisure time activities for a handicapped person is to determine a recreational or leisure activity that corresponds with the person's ability to participate in that activity. You should ask the parents about preferred activities and activities of playmates, so that you can begin your leisure time programming with things or activities the person with whom you are working is reported to have enjoyed in the past. In many cases, of course, you can simply ask what he or she would most like to do. Try some of these out in your initial contacts. An important item to remember in matching a recreational experience to a person's ability is to always have a back up activity you know the individual can participate in. If you choose an activity the person does not enjoy or finds frustrating, and you have nothing else to fall back on, the person may begin to feel inadequate to participate in leisure activities. Do not end a leisure time situation with frustration. After you have accumulated some of this information, you can then refer to the lists in this chapter or to developmentally arranged references such as Gregg (1968) for additional ideas. Gregg points out, for example, that music and sounds like wind chimes are of interest to young infants and persons who behave like three-month olds. Touching, reaching, grasping, and simple motor imitation are amusing pasttimes for persons functioning at the six-month level. Beyond this developmental age, a normal infant's interests become increasingly diverse as they are able to crawl and move about. This diversity is even greater among the handicapped because they may be more retarded in some skill areas than others. For example, a cerebral palsied person of 19 chronological years might be confined to a wheelchair, unable to make simple grasp or communicate with words but still have the intellectual capacity to enjoy attending Shakespearean plays or having literary reviews read to him.

2. Nevertheless, you can still get good ideas for entertaining activities by consulting some of the references listed in this chapter which suggest activities for preschool children of various ages.

C. Helping the Handicapped Enjoy Simpler Things

1. Many leisure time activities to which the handicapped may be introduced, require the participation of a second person, usually a teacher, parents, or helper. Perhaps the greatest service you could provide your handicapped friend is to reintroduce him or her to simpler activities and sources of stimulation they can enjoy by themselves. Things of varied textures can be rubbed against the skin and fingers. If your friend can grasp, encourage him/her to touch everything, to be aware of the textures, surfaces, and shapes of things in the house. Comment on their shape, color, size, etc., as you do this, even if you are unsure of the person's level of understanding. It is especially important for blind and physically handicapped children to be given finger paints, clay, paper for tearing, water and sand, etc., during the early years. These things are fun and they provide a medium for success; and at the same time the child progressively builds up the necessary skills to eventually handle crayons, brushes, pencils, paper-mache, etc. The blind and physically handicapped can produce beautiful works of art, from stark, string sculptures on balloons to wire sculpture. Consult the bibliography for books on handcrafts and arts for the handicapped.

2. Think about TOUCH--go outside to feel the sun and breeze all over the body, warm sand between the toes, water from a stream or wading pool, sticky pine needles, weeping willows, wet leaves, warm bricks, etc. Many of us who are not handicapped lose touch with these simple and satisfying experiences and the same may be true for the handicapped person. Endless sources of joy can be found when one appreciates the body's sensitivity to many things with which it comes in contact. When you consider that for some profoundly handicapped persons touch can be all they experience, touch is life!

3. Think about SOUND--the crackling of a fire, a babbling brook, bird calls, the crunch of fall leaves--everything. Unless deaf, even the most profoundly handicapped persons respond to music. Music is a source of great pleasure for everyone, especially for the blind and for those who are immobile. Play records, tapes, the radio, read, sing, and talk to the handicapped person, no matter how handicapped he or she is. Music lessons are a good idea to teach songs, rhythms, perhaps even a musical instrument if at all possible (see the bibliography for books on music for the handicapped).

   a. Encourage reading aloud if possible. Find out her/his interests and provide tapes and books on these subjects. Listening comprehension is extremely important, especially for the visually impaired and non-readers who derive most of their information from sound.

   b. If the person with whom you are working has verbal understanding, play guessing games (see Harbin's Fun Encyclopedia) to increase interest in observation.

      "I am thinking of something...."

      Have him/her guess, direct the eyes, or point to what you are thinking of.

4. Think about SEEING--the ability to observe what our senses feel is remarkable. If the person with whom you are working has sight, capitalize on that good fortune. If she/he is profoundly handicapped and cannot leave the home due to confinement to a bed or slant board, make that living space exciting. Try to see that space as she/he sees it. Teach your friend to be totally aware of his environment by slowly observing everything in the room. Talk aloud about what is seen. Think of every object as something to be observed, to be studied, to be contemplated with interest. Pretend to be an observer from outer space or an anthropologist. Bring the attention to shapes, design, function, color, shades, shadows, patterns.

   a. Plants are wonderful to observe-such varied shapes, textures, colors, leaves, blossoms. In fact, bring in seeds to plant and involve your friend in all aspects of growing and nurturance. She/he can water the plant everyday and observe the growing process. An aquarium or terrarium can be even more fascinating.

   b. Ask the parents for or bring posters, pictures, maps, mobiles, unusual patterns and textures, etc., which can be part of a changing room display--bring anything and everything to create a full environment.

c. If and when convenient, move the bed, slant board, wheelchair, etc., to a window. Depending upon the view, bring attention to nature (trees, plants, birds, animals, views, the rain, sunsets, clouds, etc.) or to manmade buildings, roads, bridges, cars, etc. Notice color, shapes, movement, design....

5. Think about SMELLING--Does she/he smell honeysuckle? The Eucalyptus trees? Salt spray? Grandma's cookies. Odor identification can be a source of pleasure. Can she/he observe the source of these smells?

6. Think about the OUTDOORS--Listen. Have your friend look for the source of bird calls, steeple bells, sirens, etc.

   a. Lie on the ground to observe the sky and the clouds.

   b. Wheel, carry, or walk with your friend to explore the yard and neighborhood by looking at and teaching everything. If possible have her/him describe what is seen. Describe things to the visually impaired, letting her/him touch and smell. How does a caterpillar move? How many different types of birds are around?

   c. For sighted people who are developmentally at the age of an infant, place a mobile and bright primary colors on or near the crib, as well as pictures. Continually stimulate the child's interest in looking.

   d. If possible, go outside to explore the environment. The outdoors abound in easily accessible nature resources and beautiful views. Teach your friend how to take advantage of them.

   e. Everyone's life can be enriched through an appreciation of nature. Leisure hours can be happily spent watching the sun set over the mountains, through tall buildings, along flat plains, or fishing from a wheelchair or bird watching or...

   f. Once outside become aware of the air. Does she/he feel warm sun on the body? A gentle breeze? Cold winds? Rain? Can she/he see heat waves? Wind?

   g. If at all possible, teach her/him to independently get to a neighborhood park. Almost any person would like to go to a park to swing, ride the merry-go-round, slide, seesaw - or just walk around.

   h. Teach an older person to ride a bus. Multiple handicapped adolescents can ride the bus all over the city; to the zoo, the parks, to auditoriums, and to activity centers. Remember, getting ready to go out with a handicapped person may take a considerable amount of time--plan ahead. As each person will some day be an adult, it is important to teach her/him to be independent.

D. Conclusion

1. In closing it is important to stress the importance of socialization skill for handicapped persons. Talk to your friend; teach her/him the basic social skills of small talk, how to ask someone to enter into an activity

to go somewhere, etc. Teach indoor and outdoor games that have a side appeal, but are appropriate for your friend's age and abilities. It is essential that she/he learns to independently utilize leisure time.

2. Because there are so many interesting books on arts and crafts, dance and music, and games and sports for the handicapped, the intention of this chapter is to direct you to the references in the bibliography.

3. Remember that you are a role model. Show genuine interest in whatever you do. Relax. Be yourself. Be spontaneous. Expect to have an enjoyable time with your friend. And learn and grow from your experiences. Have fun!

4. The following is a list of some of the many leisure time activities in which handicapped persons have successfully participated. Many additional ideas can be found in the references to this chapter. In many cases, a handicapped person will be fearful of engaging in a new activity and you may have to gradually introduce her/him to the various component skills until he/she has had enough pleasurable success experiences to become actively involved in the total activity. By analogy, many of us spend hours practicing a tennis swing in private before venturing onto the court for a doubles match. Similarly, you may have to spend hours teaching simple color matching and line drawing as a precursor to paint-by-numbers artwork. Obviously, this kind of practice can be fun in and of itself.

E. Activities

Active Games and Sports

Individual and Dual Sports and Games:

Badminton
Ball
Bag punching
Baseball pitching
Basket shooting
Baton twirling
Bicycling
Billiards
Bowling
Box hockey
Boxing
Calisthenics
Canoeing
Coasting
Croquet
Cross country running
Curling
Dart baseball
Diving
Exercises
Field events
Fishing
Golf
Jogging
Kite flying
Loop tennis
Marbles
Miniature golf
Model airplane flying
Model boat sailing
Paddle tennis
Quoits
Ring tennis
Roller skating
Rope jumping
Rowing
Sailing
Shuffleboard
Skiing
Sledding
Slimnastics
Snowshoeing
Squash
Stilt walking
Swimming
Table tennis

Gymnastics
Handball
Hand tennis
Hand wrestling
Hiking
Hopscotch
Horseback riding
Horseshoes
Ice skating
Jacks

Tennis
Tetherball
Top spinning
Track and field
Trampoline
Tumbling
Walking
Weight lifting
Wrestling
Yoga

Active Games and Sports

Group or Team Sports

Baseball
Basketball
Bat ball
Broom hockey
Cage ball
Captain ball
Cricket
End ball
Field ball
Net ball
Rollerskate hockey
Soccer
Softball
Speedball

Field hockey
Flag football
Football
Goal-hi
Hit-pin baseball
Ice hockey
Kick ball
Lacrosse
Long ball
Touch football
Tug of war
Volleyball
Water polo

Social Activities

Bingo
Card games: chess, bridge, poker,
gin rummy, clubs
Conversation
Dances
Dating
Entertainment
Parties
Pencil & paper games
Picnics
Playing house

Pot luck dinners
Puzzles

Scavenger hunts
Table Games:
Checkers
Chinese Checkers
Parchesi
Scrabble
Treasure hunts
Visiting

Arts and Crafts

Art metal craft
Basketry
Beadwork
Block printing
Cabinet making
Cake decoration
Candle making
Carving soap, wood, bone

Gimp craft
Home decoration
Jewelry making
Knitting
Lapidary
Leaf prints
Making: Posters, toys,
bulletins, games

Cellophane crayon craft
Cement craft
Ceramics
Chalk
Charcoal drawing
Coloring
Copper foil
Cork wood
Decoupage
Drawing
Dyeing and coloring
Embossing
Etching
Fabric decoration
Feltboard
Finger painting
Flipbooks
Furniture refinishing
Gift wrapping
Rug making
Sandcraft
Scribbling
Sculpture
Sewing
Shaving soap painting
Shell craft
Ship-model building
Sketching
scrapbooks, etc.
Metal craft
Modeling: wood, clay, sand, etc.
Models
Mosaics
Needlework
Painting
Papercraft
Pasting
Playdough
Photography
Plaster casting & carving
Plastic making
Pottery
Printing
Puppets
Puzzlemaking
Quilting
Snow Sculpture
Stage craft
Stitchery
Tin craft
Toy making
Water coloring
Weaving
Wire
Woodworking

Collecting

Autographs
Bookplates
Books
Bottles
Butterflies
Buttons
Clocks
Coins
Comics
Dolls & puppets
Etchings
Fossils
Furniture
Glassware
Indian arrowheads
Match cases
Medals
Models
Miniatures
Musical instruments
Painting
Pictures
Postcards
Pottery
Sea shells
Stamps
Toys
Woodcuts

Literary, Language, and Related Activities

Charm school
Creative writing
Guessing games
Lectures
Listening to radio, tapes and records
Public speakers
Puzzles
Reading
Riddles
Spelling bees
Story telling

Paper and pencil games
Poetry groups
T.V. shows
Writing letters

Dancing

Acrobatic
Ballet
Classic
Clog
Creative movement and Rhythms dances
Folk
Gymnastic
Interpretive
Modern
Social
Square
Tap

Vocal

Action songs
Choruses
Group singing
Singing
Quartets

Instrumental

Concerts
Listening
Music Appreciation
Playing an Instrument

Drama

Attending theater
Charades
Children's theater
Circus's
Community theater
Creative drama and play
Doll fashion shows
Dramatic stunts
Dramatizations
Fairs and festivals
Impersonation
Improvizations
Marionette
Mask making
Masquerades
Minstrel shows
Monologues
Music Drama
Videotape making
Musical comedies & drama
One act plays
Pageants
Pantomime
Parades
Plays
Puppetry
Shadow graphs
Skits
Story dramatization
Story telling
Traveling theatre
Variety shows
Water pageants

Nature and Outing Activities

Astronomy
Bee culture
Bird watching and walks
Camping
Exploration
Fire making
Fishing
Flower shows

- Caring for pets
- Cave exploration
- Clam bakes and cook-outs
- Microscope study
- Nature collections - clubs
  - crafts, games, identification
  - of animals, birds,
  - flowers, fossils,
  - insects, marine life
  - minerals, mosses, reptiles,
  - stars, trees
- Nature museums
- Gardening
- Hiking
- Indian lore
- Pet shows
- Picnicking
- Sand and snow play
- Terrariums
- Travel
- Tree planting
- Weather study
- Zoos

Excursions or Trips

- Arboretums
- Aquariums
- Automobile rides
- Botanical garden
- Bus trips
- Industrial plants
- Libraries
- Light shows
- Museums
- Neighborhood walks
- Parks
- Places of historic interest
- Places of scenic interest
- Planetarium
- Public buildings
- Visiting
- Zoo

Active Games and Sports

Low-organized games and sports for younger children:

- Birds fly
- Bull in the ring
- Cat and mouse
- Circle chase
- Dodge ball
- Forest lookout
- Fox and geese
- Frog in the sea
- Hare and hounds
- Hide and seek
- Hill dill
- Last man
- Poison
- Prisoner's base
- Rabbit chase
- Redlight
- Red Rover
- Relays
- Simon says
- Slap jack
- Spider and flies
- Snow games
- Squirrel in trees
- Tag games
  - Three deep

Activities for Severely Handicapped Persons

- Roll down hills
- Blowing bubbles
- Balloons—air or water
- Watching aquarium
- Watching fire in fireplace
- Tactile stimulation activities—grab bag of different textures
- Scratch and smell books
- Storybooks
- Cloth self-care books

Simple ball games—throwing, catching, rolling
Floating objects
Dancing
Gardening—digging—mud or sand play
Park playground equipment
Sorting objects
Drawing-felt pens, scented marking pens, crayons, chalk
Painting—brushes, sponges, potatoes, stamps, string, hands (finger paint, shaving cream, pudding), or feet
Gluing—paper, fabric, wood, pictures, sand
String objects—beads, macaroni, straw pieces, cereal
Music—listening, singing, dancing/movement

F. Community Resources

It is up to you to discover what opportunities exist in the community for the handicapped person with whom you are working—you may want to get on the telephone and call local:

1. parks department
2. library
3. churches
4. schools

Keep a list of recreational opportunities, contact people, and dates of all recreational activities going on in the community.

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